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Master's Thesis

Title:

An analysis of the ideas and beliefs regarding disabilities and inclusive education and their effect on educational opportunities for people with disabilities in Peru

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join. Disablism crosses our bodies as a vector that can take oppression to the most intimate dimension of individuals. When we are subjected at this level, the greatest threat is not realizing this is a shared experience, silently consented by the whole, and therefore that there's no privilege privately earned that can keep us safe from it (*"Die Proletarier haben nichts in ihr zu verlieren als ihre Ketten"*). For the emancipation of our bodies, for the emancipation of ourselves, I commit myself to this cause thought my work.

ABSTRACT

Today, inclusive education appears to be the most carefully supported discourse on education with respect to the heterogeneous realities and experiences that children and young people deal with, as they attempt to navigate the winding paths to their adulthood during their passage through school. For children and youth with disabilities, the institutionalization of such a discourse in their respective societies potentially constitutes an improvement in their opportunities to receive an education that positively values their uniqueness and allows them to develop their abilities without glass ceilings. However, the distance between the official discourse and the environment that shapes ideas about disability quite often doesn't correspond to each other. The influence of ideas in the construction of educational environments, moving up to the hierarchy of action in educational systems, and even upper to the characterization of interactions in the social fabric, has been subject of rigorous debate since the problematization of the post-industrial society.

However, with regard to educational policies affecting people with disabilities, the dominance of inclusive education is often taken for granted as a model and not as a discourse that is in the process of institutionalization. Moreover, in the case of societies that have not participated on equal terms in geopolitical dynamics, imaginaries about education and inclusion can be superimposed on each other, without giving them enough time, neither the conditions to assimilate the assumptions and potential consequences of the policies they commit to assimilate. Peru is a case that would fit the latter description. The objective of this study is to analyze the ideas and imaginary that would be structuring the educational offer for children and youth with disabilities. This analysis considers the logic behind the assimilation of certain ideas and/or the imperative that seems to influence the adoption of certain policies at certain times. The working hypothesis holds that it is possible that different, even mismatching logics coexist behind the ideas underlying the current inclusive education policy.

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Chapter 1: Introduction

1.1. Motivation and context of the study

The motivation behind the study is to understand the way in which ideas related to disability currently affect the existence, structure, and availability of the educational opportunities for the Peruvian children and young adults living with a disability, ultimately affecting the students' educational trajectories. This, we hope, will contribute to shed some light on the factors that shape their educational experiences. Experience is considered here the common ground for acknowledging disability/disablism, as well as well as a privileged way of entry to understand embodiment of impairments.

When we consider education and disabilities, we start to delve into de concept of Inclusive Education. This approach emphasizes equality in access to quality education for individuals from different backgrounds, taking diversity in characteristics and capabilities as a potential rather than a limitation. In Peru, children and adolescents that are considered to have Special Educational Needs (SEN) are the main target of inclusive educational policies. In theory, the national education system has integrated the inclusive educational approach and is guaranteeing the right to quality education for children and adolescents that live with a disability. However, there is evidence that, despite adopting these policies, having a disability represent a high risk for dropping out of the system or becoming un- or under-employed in the future, as well as living in poverty. If policies have been implemented, and yet the results are negative, we should ask ourselves whether there are fundamental design or implementation problems that make Peruvian inclusive education policies less effective.

Ideas are not random, but occur inside a power structure, giving it meaning and making it seem ordered and even natural for human beings. In that way, we can talk about dominant ideas: beliefs, values, assumptions, discourses. Ideas influence human behavior in all social contents and serve as a framework for human activities and production. Therefore, policies and social services are also subject to their influence, even when these activities present themselves with an image of rationality and efficiency. It is for this reason that the study of ideas becomes relevant; even when intentions are good, dominant ideas might end up hindering the rights and opportunities of social groups that are already vulnerable. Identifying and analyzing them reveals their social construct nature, creating an opportunity for reflection and change.

Returning to the relevance of experience regarding disabilities, as aforementioned, it's considered a privileged entrance for the understanding of the embodiment of impairments. As one person can't separate himself from the experience of his impairment, the Psycho-emotional dimension, understood as self-perception, identity, and life-narratives, is significantly relevant for framing the phenomena. This is particularly defiant as in several cases, the contextual disadvantages aren't acknowledged as disabilities, and therefore, they're targeted by the Other, and reflectively by the person experiencing it, as ultimately influenced by his volitive dimension, taking the blame of them. This experience acknowledged as disablism/ableism is also a form of oppression, hindering the agency of those who are subject of it. Taking the weight of disadvantages to the individual and only the individual, limits his involvement in activities, and consequently the possibility of building agency as a collectivity. Thus, the embodiment/interiorization of disablism strengthens the means of oppression of both, at an individual and group level.

Finally, this study ambitions to reconcile education policies with the experiences of those who live through their bodies the unintended consequences of them. Their experiences also witness the transformation and negotiation of ideas at a ground level, and therefore they not only complement other sources of observation on how ideas shape policies, but how they ultimately shape or reinforce disablism.

1.2. The population with disabilities in Peru

According to the 2017 Peruvian National Census, the number of people living with a disability lies at around 3,2 million individuals, which represents 10,3% of the total population. An important segment of this population faces several hardships and barriers in their daily lives: the reality for people| with disabilities in Peru is that there are less available jobs for them, their access to quality education is limited, public services such as transportation become considerably more difficult, and they face the risk of falling into poverty, if not already poor or living in precarity. It has been estimated that around one third of the Peruvian population living with a disability has felt discriminated due to their condition, hindering or preventing them from access to a right or service (Defensoría del Pueblo, 2021). The most recent official analysis of the labor market insertion and performance for the Peruvian population with disabilities dates from 2012, which already suggest ranks very low in the priority scale of labor and education policy. The report, made by the Ministry of labor, revealed that being hired is simply not a realistic option for people with disabilities. 72% of businesses declared that they would never hire a person with a disability, while 58% of occupied individuals with disabilities are self-employed. The level of educational achievement of people with disabilities is considerably lower than that of the general population, where 49.2% of the working population of people with a disability was not able to finish basic education (Ministerio de trabajo, 2012).

Comparatively, Children and adolescents with disability find it more difficult than their peers without a disability to access educational resources, acquire cultural and economic capital, and have feasible opportunities for self-development. Moreover, when their educational trajectory is interrupted or provided by unqualified educators, their overall likelihood of acquiring significant educational experiences decreases considerably. Although indirectly, preventing children and adolescents from accessing quality and relevant education constitutes an act of discrimination, increasing their vulnerability not just inside but also beyond the classroom. Unsurprisingly, studies show that children with disabilities of all socioeconomic, gender, ethnic and cultural backgrounds and identities are more prone to have their educational trajectories threatened than children without disabilities. For example, children with disabilities encounter many more interruptions to their educational experience in developing countries (Mizunoya, Mitra, and Yamasaki, 2016).

Due to the lack of more recent statistical information, it is not possible to state for certain that inclusion of people with disabilities has increased. However, having had no relevant policy changes during the timeframe between the last statistical report and 2023, it is possible to infer that, most likely, the situation remains very similar. Moreover, the pandemic promoted the expansion of informal economic strategies, with the proportion of informal employment increasing to 76.8 of the total workforce in 2021, a situation that affects mainly traditionally weaker or excluded groups, such as women and people with a disability (COMEXPERU, 2023).

1.3. The state of inclusive education in Peru

In this respect, the Peruvian education system resembles many other education systems across the world. Mandatory education is mandated for all children aged 5 to 16 years old, and the “Regular Basic Education” scheme is divided into three levels: preschool, primary education, and secondary education. By law, children with disabilities cannot be denied enrollment in this program unless insufficient vacancies are available. In addition to Regular

Basic Education, there are two additional programs, one for later education, and another for the learning needs of children with disabilities. The latter is called “Special Basic Education.” It caters to learners whose needs cannot be met by the Regular Education one, but only provides preschool and primary education. Students who complete the Special Basic Education scheme are not eligible to continue their studies in the secondary education level unless de attempt to enroll in the Regular Basic Education scheme.

The study considers that the ideas and values of state actors have structured and reproduced a system that logically excludes or reduces the opportunities and rights of people with disabilities and other minorities. Thus, it’s relevant to examine the institutional context that provides ground to the policy making process. Instability is a characteristic of the Peruvian public administration, where civic servants could be easily removed, and programs are rarely long-lived. Distrust between institutions is also a common situation, due to low levels of effectivity and efficacy. In addition to this, accountability mechanisms that allow civil society through organizations or as individuals to strength the process of policy making by binding consultation and acknowledged valuation, are poorly supported. In such an institutional context, at an individual level, actors such as workforce, from administrative servants to direct services providers, tend to act to ensure survivability; it is better for them to survive alone than to cooperate and fail together. Given this context within policy making is driven, the likelihood that core and socially significant ideals supporting policies were surpassed by instrumental and dominant ideologies crossing interactions in Peruvian society, is high. In this context, the pursuit of justice by policies is subject of constant bias and can easily loose its public purpose.

This implies that policies and services tend to have limited reach and prioritize immediate visible results over mid- to long-term change, such as building a more inclusive system and society. Public problems like the inclusion of people with disabilities, that require system-wide planning and implementation tend to not be favored, and actors do so acting rationally within the systems institutional characteristics. Public policy makers that have power in the decision-making tend to believe that not prioritizing the well-being of the population with disability is cost-effective and therefore good, and justify favoring more homogenous educational policy alternatives that focus on tangible achievements such as standard scores. Their maximization mentality prevents them from considering that their actions reproduce the inequalities that the system should be aiming to prevent.

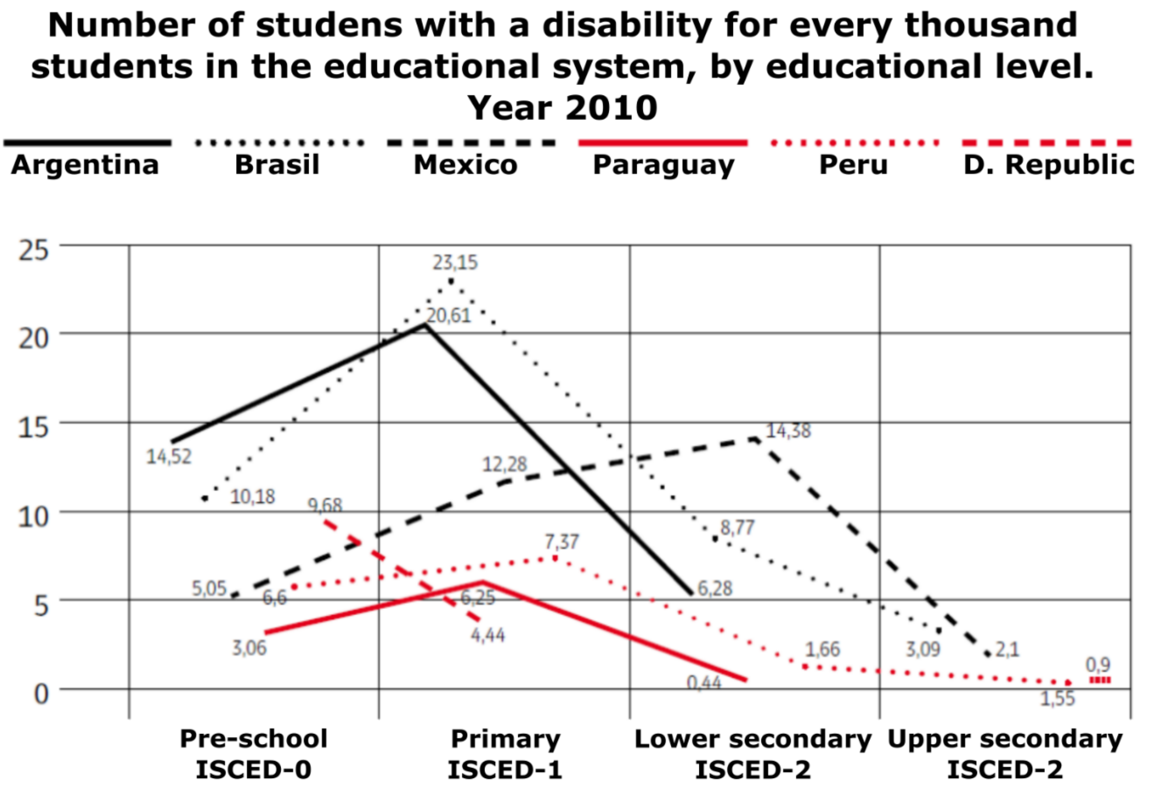
In addition to the previous statement, it's significant to remark that the instances of consultation, monitoring and integration of policies aimed at the inclusion of persons with disabilities, in practice do not have the necessary influence on appeal to a political leadership that echoes the existing shortcomings, nor do they have sufficient resources to fulfill their tasks. The creation of relevant instances for these purposes and the assignment of functions related to the inclusion of those already existing are relatively recent events, and therefore have a weak institutional framework.

1.4. The State of Inclusive Education in the Latin American Region

Comparing the situation of Inclusive Education in the Latin American region is a challenge for the researcher, since there are no homogeneous criteria, on the one hand, on how to identify the population that is considered the object of this policy and how it is implemented. On the other hand, there are also no completely homogeneous criteria on the organization of educational levels. Finally, the follow-up and monitoring systems of the countries in the region do not work with the same methodology or indicators. These were some of the various challenges reported by the Regional Education Information System on Students with Disabilities (SIRIED), an initiative project of the Regional Bureau of Education for Latin America and the Caribbean (OREALC/UNESCO Santiago), in the information gathering operation carried out in 2010.

For that report, information was required to the countries under the supervision of the UNESCO Regional office but only 6 of them returned the required information. One of the most relevant quantitative indicators, constructed by the analysis group in order to compare the implementation of inclusive educational policies that would have an impact on students with disabilities, was the access of students with disabilities to the Educational System. That is, the comparative measurement of whether children and young adults with disabilities were in or out of the educational system, and at what stage of their development. In view of the lack of information, an indicator was created to compare the attendance of students with disabilities to the total attendance of students, considering that, according to the most recent estimates made on the proportion of people with disabilities, the ratio of 1 in 10 people is becoming more and more accepted.

Graphic N°1



(Prepared by: Regional system of educational information on students with disabilities – SIRIED. Results of the first phase of implementation, 2012. Translation: Own)

The graphic represents students with disabilities per 1000 students in the educational system, in 6 countries, across the 4 standardized levels of the international classification of education levels. In most countries, as of 2010, the access of students with disabilities to the educational system follows the following pattern in order of decrease: Primary level ＞ Preschool level ＞ Lower Secondary level ＞ Upper Secondary level ＞ High school level. In relation to the access situation with respect to the other countries that are part of the report, it would only be possible to make a comparison with Argentina, Brazil, Mexico and Paraguay, since only those countries, together with Peru reveal information up to the secondary level. The access index for Peru is lower in almost all levels compared to Argentina, Brazil and Mexico, only above Paraguay. Only at the pre-school level is it able to surpass Mexico.

Regarding the dimension of equity in educational services, there were indicators associated with the guideline of "integration of students with disabilities to regular educational services". By 2010, Peru would have achieved that 62.1% of students with disabilities are in regular education. This is higher than in the Dominican Republic and Argentina. However, the quality of supply and availability of alternatives must also be considered. In Peru, the number of special schools has been significantly reduced, forcing parents to send their children to regular schools. It is not that the reduction of schools is a consequence of a change in demand.

1.5. Research objective and questions

The main research question driving the study asks about the role of ideas in the current structure and delivery of inclusive education policies for children and adolescents with one or more disabilities. Specifically, how have the ideas about people with disabilities and educational policies targeting people with disabilities affected their educational opportunities in Peru.

Further sub questions look to help answer the main question. Concretely, four such questions have been formulated:

- What is the logic behind the organization of the educational offer, regulated by the national legal framework, and the assessment of equality/inequality used for the provision of learning opportunities within it? This question seeks to understand the underlying principles and criteria that shape the educational system's organization and how they influence the distribution of learning opportunities for children and youth with disabilities.
- How have the educational offerings available to children and youth with disabilities been institutionalized? This question explores the processes and mechanisms through which educational services and programs for individuals with disabilities have been established and implemented within the Peruvian context.
- What value orientations have been institutionalized in the Peruvian Educational System in relation to the educational offer for children and youth with disabilities? This question aims to examine the underlying values, beliefs, and ideologies that influence the provision of educational opportunities for children and youth with disabilities in Peru.
- What risks and discomforts faced by children and youth with disabilities and their families within educational provision do not meet the expected expectation of well-being? This question focuses on identifying the challenges, risks, and potential adverse experiences encountered by individuals with disabilities and their families within the educational system, considering the implications for their overall well-being and inclusion.

1.6. Limitations of the study

The present study relies on texts and interviews as data sources. While interviews are a reliable source of information for case studies, their explanation power for generalizing ideas is limited. Nevertheless, the personal experiences of the interviewees happen inside structured and institutionalized contexts, therefore shading light onto their inner logics.

The field of disability studies in Peru is relatively small, and their available studies that deal with inclusion of people with disabilities in education is scarce and tends to focus on the big picture rather than exploring the micro interactions and meanings. Statistical information is also limited and not up to date, forcing the analysis process to sometimes rely on inferential reasoning to build arguments.

Lastly, I would like to point out that, while I have striven to maintain a neutral standpoint, my own situation as a person living with a disabling condition might, at some point, influence my beliefs and reasoning regarding the research topic.

Chapter 2: Literature review

"Stigma", "anomie", and "surveillance over bodies" are some examples of theoretical concepts that have been used within the social sciences to characterize phenomena whose protagonists are those whose "disability" is considered a constitutive dimension of their person, conditioning in turn other dimensions. In social life, however, there coexist different ways in which this group of people are named, varying according to the circumstances, and through which different effects can be obtained. For example, a name considered stigmatizing may have the opposite effect if it is an affirmative action on the part of a person who is part of the group, to defiantly refer to his or her belonging to the group, embracing such identity as his or her own. "People with functional diversity", "with disability", "sick", "neurodivergent", "deaf", "crazy", "handicapped", "with special abilities", "with condition", "different people", "invalids", "included", all the aforementioned denominations are used spontaneously, in institutional spaces, as a way of subversion, with scientific pretension, with political correctness, and/or with resignation, depending on who the naming subject is and what position/place (symbolic or physical) he/she intends to assign to the other.

A significant aspect to consider regarding disability as a field of study is the absence of a consensus on its operationalization. No less important, however, is that such an observation reveals epistemological and ontological challenges regarding what we call "disability", and consequently who we call "Persons with Disabilities". It is not until the 20th century that, with the international diffusion of the use of common terminologies and definitions to legislate and universalize ways of responding to this phenomenon, this concept acquires a privileged attention in terms of the need for a conceptualization that allows us to respond to the challenge of its nature.

Considering the political and social relevance it has taken on within the framework of legal protection and access to rights, the efforts for a conceptualization where the diverse needs of its application converge have made it possible to extend a bridge with respect to its historical antecedents. Thus, taking into account descriptions, labels, practices and discourses addressed in works prior to the differentiation of disability as a specialized area, it is possible to find a wide range of characteristics that are currently being recognized as corresponding to the specificity of persons with disabilities. As a result, we also find ourselves today with a multidisciplinary research field that faces an important demand for the operationalization of its components (Ustun, 2010). This demand for conceptualization is not only rooted in research, but also in the policy and management of the provision of care services (WHO, 2002).

For this research it has been decided to consider hypotheses on the process of construction of practices and discourses on disability, which have been built from a historical perspective in specialized literature. Taking into account factors such as 1) macro-social processes; 2) the relationship of the collective/individual with respect to what is perceived as "threatening" in each society; 3) the belief and knowledge systems that make intelligible what is perceived as well-being and the threats to individual/collective security; 4) the interpretation of the relationship of the attributes of certain bodies and/or their functioning, judged as dysfunctional, with the threats mentioned above; 5) the knowledge resources/techniques/technologies available to explain human biology; and 6) the type of response to the threats represented by such bodies; a review of different discourses on disability can be made based on the various aspects and interpretative approaches that can be associated with the category "disability" today (Thomas, 2007; Stiker, 1999).

Chart n°1. Proposed factors/criteria used in the identification of discourses and practices on disability, according to Stiker's work.	
1	Macro-social processes.
2	The relationship of the collective/individual with respect to what is perceived as "threatening" in each society.
3	The belief and knowledge systems that make intelligible the perceived welfare and threats to individual/collective security.
4	The interpretation of the relationship between the attributes of certain bodies and/or their functioning, judged as dysfunctional, and the threats mentioned above.
5	The knowledge resources/techniques/technologies available to explain human biology.
6	The type of response to the threats represented by such bodies.

2.1. Characterizing “Disability/Disablism” for the present study

This task also requires a conceptual definition. Faced with such a need, that of taking a conceptual definition of disability, one encounters certain methodological difficulties. Bringing together the different approaches, traditions and trajectories based on ideology, research practices, transformation objectives, etc., that have been influencing the conceptualization of disability, would lead to expressing this field of study as the gathering of several phenomena instead of just one. These phenomena would have in common to be characterized by a form of stigmatization, by chance or predestination if one takes into account the teleological dimension of the beliefs that mediate it, of individuals whose bodies intersect affectively, symbolically and/or rationally cultural conceptions of the anomic and the disruptive, within a society. However, such an imprecise definition would not be a fertile ground for the emergence of a field of research that distinguishes itself as such from others, nor would it build a collaborative knowledge that allows for a dynamic of discord and agreement on where the development of the field should turn. This situation is only hypothetical, since the field or fields of research related to disability exist, although with conflicting positions and disagreements within them.

According to Carol Thomas, if we refer to research on disability as a differentiated area of knowledge, that is, a discipline differentiated from others, a window opens from the social sciences that allows the integration of knowledge from other disciplines that contribute to making the functioning of the phenomenon more intelligible, both at the collective and individual level. It also makes it possible to trace what other phenomena not traditionally linked to the body of knowledge that constitutes the experience of disability are influencing other macro social phenomena and processes. This discipline is known as "Disability Studies". This discipline has achieved its development mainly through contributions made by the English and American academia. In both schools, "medical sociology" has contributed as much to its constitution as has "the social model of disability" (Thomas, 2007). In this line, for Jerome E. Bickenbach, there are currently two conceptual definitions that are very close, and yet aspire to somewhat different objectives, these are the one used by "The International Classification of Functioning, Disability and Health", also known as "ICF" (WHO, 2002), and the one used by "The Convention of the rights of People with Disabilities", also known as "CRPD" (UN General Assembly, 2007). Both definitions would enjoy legitimacy in public policies, as well as sharing an approach that emphasizes the social dimension of the mechanisms operating behind disability.

On the one hand, we have the widespread definition of the CRPD, which, according to the commissioners who participated in its formulation and protocol, would have been based on the social model of disability, influenced by the British school. The social model emerges as an explanatory model of disability as a phenomenon takes shape in the social settings. However, it should be noted that an explanatory model is not a substitute for a theoretical model (Thomas, 2007):

> "Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may

> hinder their full and effective participation in society on an equal basis with others." (UN General Assembly, 24 January 2007)

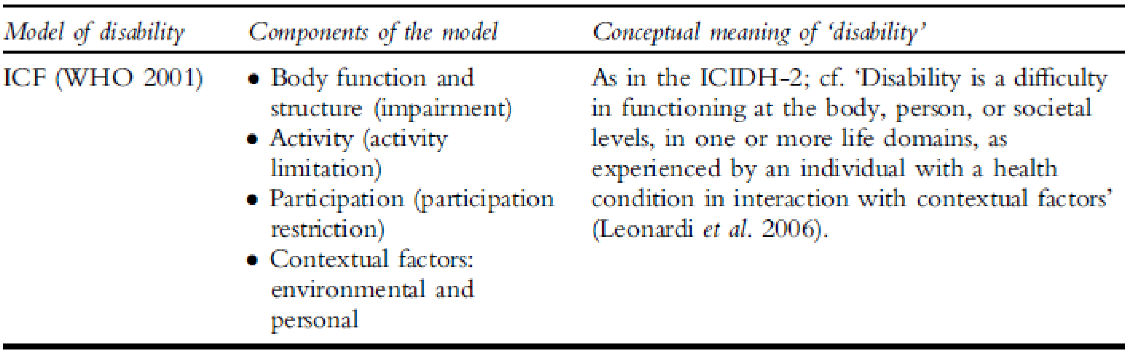
On the other hand, we have the definition elaborated for the ICF, previous to the one used by the CRPD, but also aligned to the social model. However, unlike the definition used by the CRPD that states a potential hindering of their full participation, which leads to the assumption that disability can also be reduced to an individual level (Bickenbach, 2012), the ICF emphasizes that disability is a phenomenon subject to a context, which cannot be explained only by individual aspects. Thomas, moreover, points out that the ICF concept integrates both the social dimension in the constitution of the “barriers” experienced by individuals (in the form of activity limitation and participation restriction), and the aspect of the functioning of the bodies of human beings (impairment). It would be an attempt to introduce a more neutral notion of human functioning, based on a multidimensional dimension of human health (no longer exclusively related to disease, but rather associated with the concept of well-being) (Bickenbach, 2012).

> "The ICF conceptualizes disability as a health experience that occurs in a context, rather than as a problem that resides solely in the individual. According to the biopsychosocial model embedded in the ICF, disability and functioning are outcomes of interactions between health conditions (diseases, disorders, and injuries) and contextual factors. The model recognizes that disability is multidimensional and is the product of an interaction between attributes of an individual and features of the person's physical, social and attitudinal environment" (Usten, 2010).

> "Disability is a complex phenomena that is both a problem at the level of a person's body, and a complex and primarily social phenomena. Disability is always an interaction between features of the person and features of the overall context in which the person lives, but some aspects of disability are almost entirely internal to the person, while another aspect is almost entirely external. (...)

> ICF provides, by this synthesis, a coherent view of different perspectives of health: biological, individual, and social". (WHO, 2002)

Chart n°2. Summary Chart on the Model, Components and Conceptualization proposed by ICF



Model of disability	*Components of the model*	*Conceptual meaning of 'disability'*
ICF (WHO 2001)	• Body function and structure (impairment) • Activity (activity limitation) • Participation (participation restriction) • Contextual factors: environmental and personal	As in the ICIDH-2; cf. 'Disability is a difficulty in functioning at the body, person, or societal levels, in one or more life domains, as experienced by an individual with a health condition in interaction with contextual factors' (Leonardi *et al.* 2006).

(Prepared by: Bickenbach, 2012)

The explanatory model offered by the ICF is the one that illustrates in greater detail different aspects that would be interacting in the experience of disability, using knowledge about the body as a complex of functions/structure of physiological and mental nature. This notion about the body incorporates findings made from medicine, neuroscience, linguistics, psychology, etc. The conception of this complex of functions and structure is thinking about the coverage of welfare needs throughout life, in the face of circumstances arising from its physical nature (physiological/organic), from its physical environment, from its personal situation, from its sociability, from the activities that are fundamental to access livelihoods, etc. Moreover, these aspects would be possible to identify in an individual scrutiny, since the purpose of the ICF is its application for the identification of needs. However, this model would not represent the psycho-emotional dimension of the experience of disability, such as the representations that one constructs about one's corporeality based on the perception and internalization of the effects of one's atypical functioning.

Both definitions of disability need to be presented and contrasted, since, as previously mentioned, both are part of systems that seek to integrate criteria to provide effective responses to gaps in access to rights and provision of services, among other purposes. Both systems enjoy legitimacy, although the ICF system is less used in public policy despite its high level of rigor and greater conceptual diversity. However, for the purposes of this research, the ICF explanatory model offers better conditions to identify the elements that are part of the discourses and practices of disability that I listed previously.

2.2. Delimiting the field of study of Disability research

As noted above, there are several reasons why it is not possible to reach a consensus on the conceptualization of disability. Among the reasons, it is considered that, although the current circumstances incline us to think that the meaning or meanings of disability seem more clearly defined with respect to the recent past, these should be taken provisionally, since it is a concept that is constantly being updated (WHO, 2001). Another reason for the lack of consensus could be attributed to the metanarrative that underlies explanations of how disability operates in society. By metanarrative, we mean a broadly encompassing theory that would explain how a label such as "disability" relates to the stratification of people in society. For Thomas, there are two predominant metanarratives: that of social deviance and that of oppression or social exclusion (Thomas, 2007). A third reason has to do with the discourses on disability. For Stiker, historically, certain normative and institutional arrangements constituted opportunities for discourses on disability to be woven from common meanings and values.

In this section, the main objective is to present which analytical approaches allow to analyze the ideas and imaginaries on disability that emerge from the educational offer, as well as, in the opposite direction, end up shaping it and reproducing one or more types of discourses. This will also imply taking into account the criteria that were previously pointed out in Chart n°1 in order to approach the object of study. In view of the above, a theoretical review of the paradigms of knowledge and discourses on disability will be carried out below.

2.3. Theoretical review of paradigms on disability and education for persons with disabilities

There is more than one approach available from which to disassemble the paradigms associated with both the concept of disability and disability in education, which have influenced the evolution of educational policies. There is no single proposal or a single way of reviewing the theoretical trajectory that gives rise to the different paradigms, since the evolution has not been linear or necessarily internally coherent. On the one hand,1) there is a significant gap between the principles and policies valued as morally valid in the treatment of persons with disabilities, which a State or group of States seeks to incorporate and certify, and the practices and systems that end up being woven along the way. On the other hand, 2) within the development of specialized knowledge on disability (including conceptual approaches based on historiographic reviews), variables such as openness to the exchange of perspectives between disciplines, the search for internal congruence, and feedback from the members of this community of specialists on how the ideas that the community itself has conceived have been put into practice play a role. Both dimensions are in permanent communication, influencing each other.

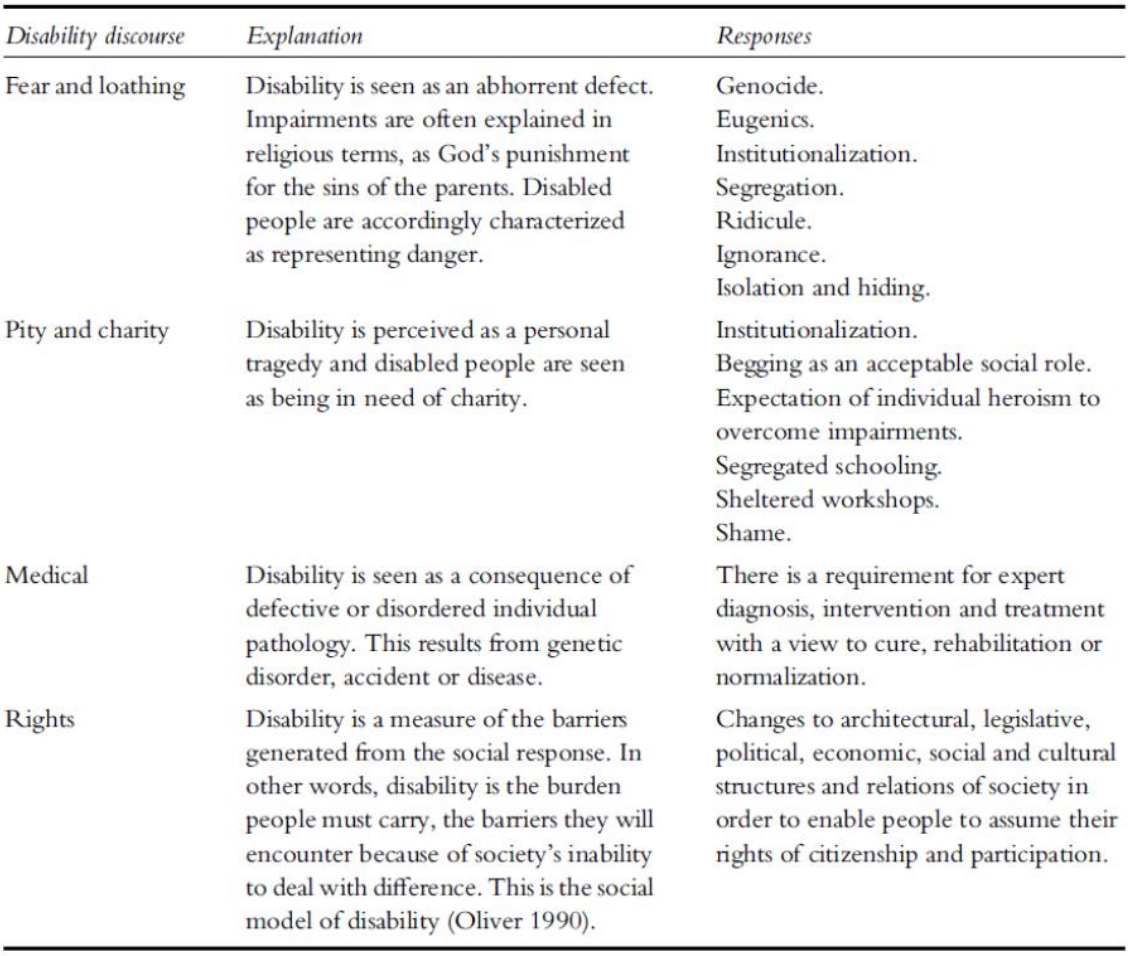
Regarding the former, authors such as Biermann and Powell find it relevant to consider the concept of "path-dependence" in this issue, to explain why education systems have mixed characteristics regarding the conceptual approach to disability with which they show signs of aligning themselves (Biermann, 2016), especially in times like the present where most countries are positioned within the political horizon of "inclusion". The concept of "path dependence" explains why in processes of institutionalization of a policy that is presented as the product of a political and social consensus, it suffers alterations in its implementation when it is taken to more localized contexts. Both local beliefs and the organizational needs of the field of action often differ from the ideological and transformational commitment contained in the policy, in this case in relation to disability. Both factors would explain why there is no progression that assumes that an educational offer at time "A" will eventually be replaced at time "B" by an absolutely better one.

Regarding the latter, a series of turns can be identified in the development of thematic knowledge that follow a pattern similar to what Karl Popper and Thomas Kuhn identified as the factors that originate paradigm shifts in science. Thus, it seems that sometimes it is an ideological system in conflict with the dominant one that tips the balance towards certain turns. At other times the opportunity arises for the utilitarian mediation of ideas and values that enjoy greater legitimacy because they have greater universal value than those already taken for granted. In addition, some ideas may have a disruptive value that empowers the dominated class by confronting the morality underlying the established social order, inspiring movements that bring together a broad majority (Stiker, 1999). Considering the above considerations, in order to approach the study of the ideas and imaginaries that shape the attention to people with disabilities in educational systems, it is necessary to distinguish two distinct fields. One focuses on 1) "disability" as an experience and as a way of knowing/perceiving in society; and, 2) the other focuses on educational practices targeting people with disabilities.

2.3.1. Disability

With respect to the first field of study, that of disability, Moore and Slee reconstruct what would be for them the discourses on disability that have been identified by other authors. The discourses would have been recreated through the historical analysis of forms of knowledge and relations of domination built around the characterization of people with disabilities. The following table is the result of this reconstruction:

Chart n°3. "Summation of Disability Discourses" Chart



Disability discourse	*Explanation*	*Responses*
Fear and loathing	Disability is seen as an abhorrent defect. Impairments are often explained in religious terms, as God's punishment for the sins of the parents. Disabled people are accordingly characterized as representing danger.	Genocide. Eugenics. Institutionalization. Segregation. Ridicule. Ignorance. Isolation and hiding.
Pity and charity	Disability is perceived as a personal tragedy and disabled people are seen as being in need of charity.	Institutionalization. Begging as an acceptable social role. Expectation of individual heroism to overcome impairments. Segregated schooling. Sheltered workshops. Shame.
Medical	Disability is seen as a consequence of defective or disordered individual pathology. This results from genetic disorder, accident or disease.	There is a requirement for expert diagnosis, intervention and treatment with a view to cure, rehabilitation or normalization.
Rights	Disability is a measure of the barriers generated from the social response. In other words, disability is the burden people must carry, the barriers they will encounter because of society's inability to deal with difference. This is the social model of disability (Oliver 1990).	Changes to architectural, legislative, political, economic, social and cultural structures and relations of society in order to enable people to assume their rights of citizenship and participation.

(Table prepared by: Moore, 2020)

According to this summary, it is possible to distinguish historically different ways of understanding disability in Western civilization, and with it, a wide range of social responses respectively (Moore, 2020). From antiquity, in those societies constituted by a social order dominated by a belief system based on a supra-natural order, in particular but not exclusively those where the Jewish and Greco-Roman cultures of the classical period were gestated in antiquity, the discourse of "Fear and Loathing" is the first social form with which evidence on the perception of disability is distinguished. Through the division of normative-normal bodies and defective-different bodies, persons with disabilities become objects of revelation of the divine order, by "making visible" the risks of transgressing the norms imposed by supra-human forces to govern the lives of humans. The transgressions could have been committed by the subject himself or by his ancestors (Stiker, 1999). The social response to this discourse is diverse, ranging from genocide and eugenics to segregation, institutionalization, and isolation. This discourse, originally associated with the interpretation of divine will, eventually outlives this source of meaning. This discourse based on fear and loathing as triggers, by gathering feelings that have an ontological value for human beings in society (Hughes, 2012), is preserved along with this representation of transgression and social deviance attributed to people with disabilities. In other words, acquired responses about the visibly different bodies of people with disabilities continue despite social transformations such as the rationalization of religion and the establishment of a morality centered on individual action.

Something particular to this discourse and period of genesis is that there would have been a differentiation between people with amputations, bodies perceived as deformed and monstrous, people with incurable diseases, and people with disabilities. Among people with disabilities there was a differentiated treatment between those whose disability was of a sensory nature and those of an intellectual nature, for whom social responses were favorable as opposed to the rest. Fear was a constant element since the visibility of all these groups mentioned above, with the exception of amputees, was a common interpretation of disturbance of human nature, which threatened the safety of the group. The aberrant were to remain within their homes in the care of their families, as they could disturb the purity of the rituals in the places of prayer/worship. The sick could receive purity rituals but could not mingle with others so as not to contaminate them (Stiker, 1999).

The following identified discourse on disability is distinguished by the influence of Christianity, already institutionalized under Roman domination, on the perception of people with disabilities. Such institutionalization takes shape under the patronage of the Roman Empire, when the Church emerges as an institution that distinguishes itself from others by ruling over the spirituality and salvation of people, and, with it, this discourse develops and undergoes some transformations throughout the period corresponding to the Middle Ages in the European civilization. Through the feeling of Pity and the practice of Charity, people with disabilities would have been instrumentalized as a means to access individual salvation. People with disabilities were considered subjects who needed the charity of the collective to survive, due to their poor fate of being mixed among the begging of the poor, and being doubly exposed as a representation of social marginalization and moral aberration (Stiker, 1999). The discourse of Pity and Charity alludes to a broad system of donations based on the conception of Charity, which implied covering a portion of the survival needs of those living in conditions of social marginalization. People with disabilities and the sick would also have been sheltered within this system since they would share the living conditions of the poor.

According to Stiker, with the appearance of pests and plagues, a good part of the population lived on the margins of the cities, as in Paris, where they were distributed in different communities of "social outcasts", sharing poverty and beggaring as a means for living. Epidemics, caused by diseases that were transmitted with great ease due to the greater interdependence between burgs and cities in the Middle Ages, had left many survivors with permanent sequelae (sick and disabled people), who were part of the new normal. Through poorhouses and hospices, an ethics on almsgiving was nurtured from the core of Christian spirituality, sustained for a time by the widespread acceptance of the belief that the poor, especially the sick and disabled living in poverty, constituted role models of Christianity and closeness to Christ. Sick and disabled people entered the hospices, supported by the Charity, for short periods of the day, and then returned to the streets, where they were exposed but equal, all under the mantle of poverty. This meant that outside of the enclosures, not everyone was considered a beggar without distinction. To a certain extent, it can be said that in that period they received a symbolically positive status because of the Christian beliefs of the time. This ethic would have been disregarded later when times of peace gave way to wars, famine, and the most lethal plagues (Black Death, cholera, and tuberculosis).

Stiker argues that in the face of fear and uncertainty about the origin of the plagues, combined with fear of the violence in which the poor had begun to become involved in their revolts, the free transit of this population ceased to be normal as it made way for progressive full-time institutionalization. Sick and disabled people were associated with the origin of the plagues, but their marginal situation and inability to comply with forced labor, which was beginning to be implemented as a control measure, meant that they were relocated to specialized establishments. In France, for example, people with blindness were placed in a different establishment from the rest of the disabled and sick people. Given this explanation, the wide range of social responses to this discourse on Disability found in the table elaborated by Moore and Slee is understandable, due to the changes occurring throughout this period with respect to the judgment and degree of differentiation made about people with disabilities. Disabled and sick people received care and some forms of treatment that were practiced at the time to counteract their ailments, and were also the object of evangelization, when the establishments were run by religious orders.

There is a fairly broad consensus on the following two discourses presented in the table, both among researchers and leaders, as well as in institutional documents of governmental and non-governmental organizations that focus on disability policies. For all of them, both discourses would constitute two major paradigms of national disability policies. These are the "Medical" and the "Rights-based" discourse. With respect to the first, the Medical Discourse, its emergence is linked to the birth of medicine as an area of specialized knowledge, based on the explanation of natural processes, such as physical and biological phenomena, as a causal relationship that can be found through observation (Stiker, 1999). Medical discourse underwent several transformations since its genesis in the Enlightenment era, until the beginning of the 20th century, according to Stiker. This would be a period covered by constant changes. However, Stiker differentiates the following period, where the medical discourse undergoes a transition, with the First World War as a milestone, towards the Rehabilitation discourse, which would have both legal and sociological implications. For Moore and Steele, however, the transition from the Medical discourse to the subsequent one revolves around the Disability Rights paradigm, which, for many who follow this thinking, would emerge to eventually take the place of the Medical Discourse as the dominant discourse. It will be seen below how, according to the hypothesis developed by Stiker, the conception of Human Rights would be a consequence of the Rehabilitation discourse. The period of the emergence of medical discourse also coincides with an unprecedented expansion of the impact and scope of the discoveries, technologies and innovations that took place between the end of the Middle Ages and the beginning of modernity onwards, so that the discourse itself undergoes transformations hand in hand with the transformation of the relationship between science and human relations.

According to Stiker, medical knowledge also becomes a source of authority that replaces that of Christian morality in its claim to truth. As previously mentioned, phenomena such as the functioning of the human body became the object of interest for the imperative of the causal relationship from observation, leaving aside more and more imagination as a means of elaboration of explanations. This has more than one direct impact on the conception of people with disabilities. According to Stiker, monstrosity ceases to be a relevant concept to identify people with disabilities, since deformities and diminished bodily faculties began to be conceived as deficiencies, losing the power of the fantastic symbolism of "monstrosity". In this context, people with disabilities also found themselves in the midst of another transition, that of the logic underlying their institutionalization, and the centrality of the State as the actor organizing this process. From hospices and institutions governed mostly by religious orders, people with disabilities began to be relocated first to hospitals, which in turn began to specialize in order to differentiate the sick from those with impairments.

In this period, according to Stiker, the idea of the combination of discipline and education as a means of integrating those with a certain degree of reduced functionality also arose, as opposed to the care that dominated the previous discourse. Likewise, the objective of treating people with disabilities in hospitals would have meant a change of perspective regarding the acceptance of what was perceived as dysfunctional within the horizon of normality in human coexistence. The new imperative would be to try to create a narrower standard of normality. Hence the emergence of institutions such as asylums, an intermediate between a place of treatment and isolation from the rest of society; the use of technologies, techniques and pedagogies to convert people with disabilities into functional individuals above a lower limit, as was the case with the birth of orthopedics in the service of the Trade and Vocational Schools; and the transformation of care into assistance for those who could not be restored to society as normal. For Stiker, this discourse and period of domination is generally characterized by the use of medicine as a unit of measurement of deviation from normality, and the introduction of the ideas of health, weakness and the principles of classification of subnormality.

The discourse that follows the medical discourse, in order of appearance, differs for Stiker with respect to Moore and Steele's proposal, as previously mentioned. Stiker considers that the aftermath of World War I generates the conditions for the development of a new discourse on disability, in large part because the surviving ex-combatants, after their return, are the origin of conceptions such as moral obligation and reparation for their respective societies. In the case of France, a history that Stiker analyzes with particular attention, the war is seen as a catastrophe whose consequences include those maimed by the war. In order to offer various forms of reparation, ranging from therapies and prosthetic devices to massive social assistance for the number of ex-combatants, it was necessary to implement an administrative system to regulate and measure the damage to be repaired. In view of this, rehabilitation gave rise in parallel to the emergence of a legislative discourse on disability that previously would have had no need to exist. Regulating in favor of people with disabilities, typifying and standardizing procedures, on the one hand, and classifying the different impairments on the other hand. Just with the administrative system that classifies and regulates assistance to amputees and eventually progressively extends to incorporate other forms of disability, a legal order is being woven that ends up imposing itself on the more organic understanding of disability that had previously prevailed.

This period also saw the deepening of compulsory education as a state policy. Stikler points out that the proliferation of legislative discourse to impose a new order on disability led to the role of the physician as the bearer of truth being eventually replaced by the birth of consultative commissions whose function was to validate and decide where to place the person with disability within the specialized structure that was being created. One type of commission, in the French case, is the creation of Special Education commissions for children and adolescents, which offer technical criteria for standardization, but also have the final word on the means by which persons with disabilities, according to their degree of dysfunction and their characterization, are redirected to institutions that will be able to minimize their dysfunctionality as far as possible with respect to the conditions necessary to live in society. This gives rise to the emergence of specialized services in the school, together with specialized formulas designed for these services. For Stiker, all this would evidence the growth of the need for control over what are considered abnormal situations in which people with disabilities are involved, and at the same time the corresponding growth of de facto control. Underlying all this would be mechanisms of denial of disability, through the implementation of adjustments and integration.

For Moore and Steele, rehabilitation and the pretension of normalization of the culture and dysfunctional expressions of disability are still part of the medical discourse. However, for them, there is a differentiation with respect to the medical discourse in the emergence of a legal discourse that enables a regime of protection and civic integration of people with disabilities. This would be the rights-based discourse, which is closely linked to the proposal of the social model of disability that emerges from the activism of the English academy and the human rights movement that was also involved during the 80's, according to Carol Thomas. Compared to Stiker's postulate, the Human Rights discourse would be a consequence and a subdivision of the Rehabilitation discourse, since they coincide in that the discourse on the Rights of Persons with Disabilities that has greater political support and of the civil society involved in activism, currently there is an imperative on the need to transform practices on architecture, urban design, the requirements for the implementation of policies and the design of laws, which should seek to integrate persons with disabilities in their purposes.

On the other hand, this discourse would propose, from the rights approach, the need to transform the legal, cultural, political and social structures that would be allowing the reproduction of disabling situations, since disability would no longer be attributed only to the particular circumstances of a person. However, here Stiker would have a difference with Moore and Seetle, since for the former, by forcing the label of disability in formal contexts, the perception that people with disabilities carry the burden of the cost of normalization is diminished. It would create the appearance that if discursively everyone recognizes that people with disabilities are subjects of rights, then there are no longer obstacles that relegate them to a space of marginality in the imaginary of society. In addition, there would be strategies in language and legal arrangements that continue with the partial recognition of the normality of those who have a disability. People who have "mild cases" could be absorbed into normality, but not those who are characterized as "severe cases".

2.3.2. Education and Educational Policies

As mentioned in the previous section, the discourses on disability related to the creation of educational practices can be traced back to the creation of institutions that had a different purpose than education as we understand it today. The set of strategies and techniques that contributed to the creation of the first schools designed for the care of children and adolescents with disabilities, according to Stiker, were first designed to instruct people whose disability was of the sensory type, and to give them access to the cultural background that they considered substantial to be part of society (Stiker, 1999). It is possible to find evidence that people are blind, deaf and deaf-mute, since ancient times, would have been subjects of a privileged appreciation with respect to other types of disability (Stinker, 1999; Goodney, 2018). They had bodies that were perceived as equally capable, unlike people with amputated limbs or malformations, and on the other hand they seemed to have their intellectual capacities intact unlike those who were considered retarded.

In the institutionalization of a specialized pedagogy for people with disabilities, the main motivations would have arisen from the practices of care and evangelization by members of religious orders in Western Europe, particularly those influenced by the Catholic Church. Between the institutionalization of the hospices and the emergence of the design of pedagogical strategies to make accessible the knowledge that was considered indispensable for the development of the intellect for people with sensory deficiencies, the basis for the creation of Special Education Institutions arose. According to Stiker, the work of university teachers, particularly those who also shared sensory disabilities, led to the development of special techniques for the teaching of mathematics and other sciences. By the end of the 19th century, several states already had pioneers in the creation of alternative language media, such as Braille and sign language, whose creations spread rapidly. Vierestreate and Söderfeldt consider that the consolidation of statistics as a means of population control during the 19th century made it possible to visualize the magnitude of people with conditions characterized as problematic for society (Vierestraete, 2018). This coincided with the dissemination of manuals or guides for the teaching of subjects considered essential for humanistic education to people with specific conditions such as Deaf-blindness.

However, a school for minors, covering the needs of childhood and early youth, also conceived as part of a policy and system of education for the general population, which also managed to homogenize behaviors in interpersonal relationships in a differentiated way in different population groups (due to their social stratum, proximity to marginality, ethnic-racial origin, etc.), and finally managed to legitimize certain forms of authority (nuclear and patriarchal family, state, market, ruling class, etc.), did not consolidate until the end of the 20th century (Finkelstein, 1984). Prior to this period, the development of the instruction of minors would have had a relatively divergent development from one society to another. It is in this context that Special Education is consolidated as an institution that targets a specific population group, as heirs of the pedagogical strategies, techniques and specialized language previously developed for those who were perceived as part of a culture of social deviance, non-functional to the heart of civilization. Combined, they offered at that time the most effective results for the standardization of the abilities of people with sensory disabilities, both children and young adults (Stiker, 1999).

In the literature corresponding to research on knowledge paradigms and discourses on education for people with disabilities, authors usually start from this moment, which coincides with the disability rights movement, and with favorable conditions for the regulation and standardization of the instruction of children and youth with differentiated and measurable attributes (Stiker, 1999). Authors such as Finkelstein, who attempt to reconstruct the different discourses on education in the United States, identify a particular group of literature related to this phenomenon that focuses on the historical development of the expansion of government involvement on education through public education policy. One approach within this literature is that of the institutionalization of child-rearing norms. This characterization of the ideological component underlying schooling is based on the different disciplines involved in reflecting and recommending which aspects of personal development and well-being should be covered by the school (Finkelstein, 1984). However, this would not be the only interpretation available from the review of the available literature on the discourses on the institutionalization of education.

In the case of educational policies for people with disabilities, these are usually seen as an object of interest within the available literature on "Sociology of Medicine and Illness" and "Disability Studies" (Thomas, 2007), among other research traditions from which it is possible to reconstruct the different courses on disability. However, for the genre of disability literature grouped under the name of "Inclusive Education", educational policies are a central aspect in its development, since it arises in the midst of a discourse on the role of the state that sees access to education as an enabling condition for access to other social and individual rights. The context of the Cold War created competition between geopolitical blocs, and the universalization of education promoted by the Soviet Union influenced the other bloc because of its capacity to respond to the social demands of the most marginalized populations, with the difference that civic education should also be promoted to normalize the values discursively considered the heart of liberal democracies. It is in this context that the discourse of Social Justice or Social Rights acquires influence in the legal system of international mediating bodies such as the United Nations-UN, focusing on the role of schools and access to education as a means not only of vertical mobility, but also of reducing social gaps and segregation.

The research grouped under the name of "Inclusion" or "Inclusive Education" involves a willingness to dialogue about the prism through which knowledge is constructed. This disposition implies an exercise of epistemological vigilance on the assumptions and consequences of educational practices on students, especially those with disabilities, which would reproduce or create new conditions of inequality. Based on this reasoning, it is possible to carry out a review of the ideas, concepts and discourses that are part of the educational policies that would have regulated access to education for people with disabilities to date (Biermann, 2016). In addition to this, from this exercise, public policies have been joining an educational reform movement under this critical view on orthodox and insufficiently self-reflective educational practices, incorporating concepts, changing the language, and designing techniques that would ensure the institutionalization of the discourse on inclusion in the educational system, contrary to the strategy that combines segregation and specialization.

Those who research taking inclusion as the paradigm that guides their interpretation of educational practices, differentiate the concept of "Special Education" from that of "Inclusion", highlighting their incompatibility (Moore, 2020). Those educational practices that would be organized under the label of Special Education would be identified as a consequence of the medical and rehabilitative discourse. As previously mentioned, pedagogical practices, according to Stiker, would have been originally developed for people with disabilities who had especially sensory impairments. It would have been in response to the need for them to have access to culture and to be able to take part in sociability, even if in a marginal position. At the beginning of the 20th century, another background occurred, which was the birth of classification systems and the need for resocialization of people with diminished functionality and amputated limbs, which also implied making people economically competitive as workers. The first conceptualization of Special Education would emerge together with the consolidation of educational policies aimed at covering the need to universalize schooling. This process occurred heterogeneously in different states, but it can be identified from the 20th century onwards as the period in which it became generalized.

Given the background, in developing specialized pedagogical techniques for teaching children and young adults with disabilities, the concept of Special Education arises, on the one hand, as the set of teaching techniques that require to be mastered to instruct in knowledge considered basic. On the other hand, the concept of Special Education also lends itself to how the educational system organizes provision of education for people with disabilities. All this required the development of a regulation and the realization of an administrative division (Biermann, 2016). Since the classification of impairments arises as a necessity for the placement of people with disabilities in conditions designed for their rehabilitation, the practice of subdividing and separating is also assimilated by the notion of Special Education.

The notion of Special Education, moreover, would be subject to transformations since its institutionalization. It is a concept in force in many educational systems, and is instrumentalized for the creation of differentiated systems where different types of educational offerings can be provided for children and young adults with disabilities. Among the different variables that influence its differentiation, such as the different specializations that have been outlined in higher education grouped under the professional title of "Special Education", there is also the legislation on education and the specialized language that officializes the attention to people with disabilities. On this aspect, it is possible to recognize the echoes of those practices reviewed by Stiker on the division made on people with disabilities under the new criteria of normality, after the First World War in France, in which the need to restore people as workers would have underlain. By classifying individuals within a graduation of disability in which parameters were established to separate "mild cases" from "severe cases", the conceptualization of Special Education also came to absorb this division. This division would contribute to legitimize the idea of a subnormality, an exceptional situation in which it is not possible to achieve the objective of social integration within the new parameters of normality (Stiker, 1999).

This hypothesis coincides with the characteristics of educational legislation on special education and the measures for its implementation that have been promoted from the mid-1990's to the present day, through interstate agreements under the mediation of institutions such as the UN/UNESCO, the OECD, and regional agencies of education policy such as the European Agency for Development in Special Needs Education (D'Alessio, 2019). Through those tools, which enjoy the status of truth thanks to the logic of legislative discourse, it has contributed to the consolidation of the existence of "exceptional conditions", reserved for those students who fit the characterization of "severe cases", but which, thanks to the means of validation, are accepted as reasonable.

The problem of lack of access to schooling for people with disabilities forced to take the educational segregation of Special Schools as a measure not only discordant with new standards of equity such as self development and citizen participation, but also insufficient to solve the problem of universal access to education. Thus, the notion of "Special Educational Needs"-SEN was consolidated, differentiated from that of "Special Schools", when the integration of students with disabilities to schools that did not offer exceptional conditions was proposed, to which the label of "mainstream schools" was assigned, and "mainstream students" to students who did not have disabilities, in this new proposal (OECD, 2003). In the heat of the movement of people with disabilities in England, the theoretical tradition that gives birth to the social model of disability, enters also the field of educational policies. As it was proposed that the environment played an active role in disability, the school, understood as a settled environment, would also become a disabling variable when needs arosen in the teaching context are not identified neither covered by the school. This identification and response strategy would be differentiated as "Special Educational Needs", and it would incorporate not only the needs of students with disabilities, but also other types of challenges that would be grouped as "Learning disabilities and Disadvantages". However, despite being differentiated, both notions remain associated with the broader conceptualization of Special Education.

As the demand for greater conceptual accuracy grows, as well as for theoretical frameworks that conceptually articulate all the elements that are part of the educational system reform proposal as a means of foundation, the conceptualization of Special Education becomes more complex. To a large extent, this demand is a response to the growing influence of the "Inclusion" discourse, whose appearance in the field of educational policies is not new. However, rather than becoming prominent as a framework of top-down implementation supra-state technocracy, the notion of "Inclusion" had its own development in the realm of social and political rights debate, just as it had had its own space of academic debate (Biermann, 2016).

The notion of inclusion had been the subject of inspiration for educational reforms in South America as part of the critical pedagogy movement, of which Paulo Freire was one of its most prominent drivers. This movement emphasized the importance of education as a means for the emancipation of communities that were subject to social oppression due to their ethnicity/race and poverty. The notion of "Inclusive Education" achieves its legitimacy rather through institutional channels. It made its appearance in multilateral agreements with the "Education for All" agenda aimed at expanding access to education for those who were traditionally left behind, especially in the group of countries identified as "developing countries". By the mid-1990's "Inclusive Education" already emerged as a proposal with its own agenda that sought to consolidate itself as an alternative to Special Schools, which promised greater viability over the high operating costs that the second strategy implied, and therefore did not make it a universalizable strategy. "Inclusive Education" proposed that adaptability measures should be provided in all schools to respond to the special educational needs of students. This proposal was later endorsed by the Convention on the Rights of Persons with Disabilities.

Chapter 3: Theoretical Framework

3.1. The role of ideas in policy design and implementation

In any topic that is of interest or relevance in social life, individuals might think that the names, terms, words, and symbols are universal and have clear meanings, yet the meaning and symbolic content of the elements that make our life are in constant construction and negotiation. To act and influence their social environment, individuals need to rely on understandable concepts, categories, and symbols that make sense in the context and time that they are embedded in (Berger & Luckmann, 1966). Ideas are not disconnected from other relevant explanatory elements of political life such as psychology, institutions, or structure, and neither are they disconnected from the concept of individual interest (Béland, 2015). As part of the elements that orient social and political action, ideas have been increasingly recognized as just as relevant as utilitarian rationality or institutionalized organizations and rules for explaining political behavior and outcomes (Béland, 2015; Mehta, 2010). Ideational researchers then, complement the study of the mechanisms of policy making by unpacking and explaining the content of policy choices (Mehta, 2010).

In general, ideas can be understood as institutional frameworks embedded in societies and their existing institutions (Swinkels, 2020). Understood as frameworks, collections of ideas can affect individuals from “outside” to constrain or enable their actions. As values or beliefs, they behave as institutionalized rules, and they can serve as frame for decision-making in moments of uncertainty such as moments of punctuation that enable change, effectively restricting the possibilities for path variation (Mehta, 2010; Swinkels, 2020). In a similar way, it is also implied that ideas-as-frameworks will be affected by path dependency, and ideational change will not occur randomly but rather follow similar mechanisms as other types of institutions (Swinkels, 2020).

It is important to categorize and typify ideas to study them. Mehta divides ideas affecting the policy process into three different analytical levels, considering that each level will have its own rules of interaction (Mehta, 2010). The three defined levels are:

- Ideas as problem definitions
- Ideas as policy solutions
- Ideas as public philosophies or zeitgeist

Ideas as problem definitions constitute ways to make complexities understandable for all individuals. Most deliberations will take place at the moment when a certain topic is being constructed as a social problem, as the set of ideas that become the dominant definition of a problem will directly affect the set of possible solutions to propose. Ideas as policy solutions are centered on accomplishing certain objectives. These objectives must respond to a specific problem, and the idea of a policy solution needs to have political, administrative, and policy appeal.

Becoming appealing is not just a technical matter; it will need to resonate with past implemented policies (and therefore be shaped or framed by them), as well as be supported by the political context and public mood or beliefs. The latter are encompassed in the concept of ideas as public philosophies or zeitgeist, which can be understood as meta-ideas about social and political life. Public philosophies are ideas that make sense of a public policy's purpose in light of beliefs or assumptions about how society functions or should be, so they could be also understood as meta-problem-definitions. Zeitgeists are core cultural, social, and economic beliefs that are widespread and are not questioned and tend to have a cyclical flow.

The three different categories of ideas can interact and affect each other. For example, Ideas about policies could expand the definition of problems depending on their design, eventually affecting public philosophies about that topic, and this in turn would affect future ideas about both policies and problems.

In terms of the methodologies for studying the role of ideas in the policy process, Swinkels divides different methods depending on the functions that ideas have (Swinkels, 2020). For Swinkels, ideas can have three kinds of functions:

- Ideas as heuristics, serving as references for guiding individual decision-making processes
- Ideas as strategic tools, functioning as elements that build up discourse for (re)interpreting social reality
- Ideas as institutional frameworks, becoming embedded in society as institutions, or within existing institutions as collective understandings

Heuristics are cognitive short-cuts. In ideational research, they are actors' beliefs, cognitive and subjective elements that simplify action and decision-making processes in daily lives. Focusing on heuristics implies understanding the role of political actors' beliefs on political outcomes such as policies. Strategic tools imply instrumentality; ideas are consciously and rationally utilized by actors as a means to an end. Usage of ideas for building discourse is, again, framed by the institutional context and acquire meaning depending on the institutional setting. Institutional frameworks comprise ideas situated at a structural level. Hegemonic discourse such as neoliberalism or liberalism precepts are examples of structurally embedded ideas. They can be a prevalent event throughout political crises, and frame individuals' way of understanding the "correct way" of how to do or interpret elements of social life.

Another important example of hegemonic discourse would be ableism, which is still the dominant set of beliefs surrounding disability, effectively filling the "disabled" label with content that ends up denying or obscuring diversity, placing blame on the individual with a disability for not being "abled", and redefines inclusion as pity or charity work, which would be a good deed yet should not be a priority nor a core social and political concern. Accordingly, some scholars are currently challenging ableism by showing how its labels, beliefs and values serve to obscure the range of different experiences that 'disabled' people experience. Without further scrutiny on the distinctive limitations experienced that are linked to some dimensions within the specificity of some contexts, and on how apparently contextual disadvantages commonly experienced by some aren't acknowledged as disabilities but targeted instead as related to their volitive dimension, an increasing symbolic violence would go unnoticed.

Methodologies for studying ideas vary according to their function (Swinkels, 2020). Ideas as heuristics are studied through means that allow access to actors' cognitive processes. These include surveys, interviews, and qualitative content analysis of text, as well as others. For ideas as strategic tools, methodologies such as biographical and discourse analysis are relevant for understanding the function of ideas in discourse and measuring the presence of ideas in individuals or group trajectories. Finally, for studying ideas as institution, content and discourse analysis can also be useful for analyzing meta-discourses.

3.2. Discourse analysis for the study of the role of ideas in policy design and implementation

As pointed out by Swinkels, discourse analysis is relevant for studying policy design and implementation (Swinkels, 2020). Discourse analysis focuses on how particular situations or phenomena are represented in text; they are constructed forms of knowledge about the world that act as frames of reference (Joe, 2013). Several discourses tend to exist at the same time, yet in certain contexts and conditions, one tends to become dominant. Discourses can become intelligible from studying speech or text, and therefore it is possible to examine a policy from within to understand the way they enable and constrain its construction process. Analysis of discourse is performed by "asking questions" to the text, akin to a questionnaire, which the researcher utilizes as a guide to reconstruct discourses and understand their role and effect on the policy process.

3.3. The "disabled" discourse in public policy

According to Wendell (1996), the main problem that prevents socio-political reforms from dealing with the restrictions and barriers that people with a disability face in daily life, is precisely that proposed policy solutions and implementations are born from an "othered"-constructed concept of disability. "Othered" means, in this case, that disability becomes a separated part from the "normal and natural" by definition, making it very difficult from the start to design and implement policies that actually integrated people with disabilities in an inclusive way, therefore maintaining the existing inequalities instead of combating them.

Both oral and written texts of any nature are framed by ideas and beliefs disseminated by the dominant culture, so it is possible to analyze formal and informal texts to understand dominant discourses. As Reinikainen points out, dominant definitions and concepts of disability have been mostly imagined, produced and disseminated by regular non-disabled individuals, so their cultural products become a relevant study material to understand the source of inequality (Reinikainen, M., 2006). Reinikainen explores the way in which stories written by non-disabled individuals produce particular meanings for being “dis/abled”, both through what is said as by what is omitted. Her findings show that non-disabled individuals had incorporated elements from different discourses, yet the individualist and medical centered discourse still remained dominant, and that the particular discursive combination that they used varied according to the characteristics of the disabled individual that they were referring to. For example, a single individual may use a more positive and inclusive discursive narrative when referring to a male with a physical disability, and a less inclusive and more medical discursive approach when talking about a female with a mental disability.

Chapter 4: Methodology

In the previous chapter, the theoretical framework also explored the possibility that certain methods can help to approach the object of the study. In the current chapter, the overall methodological strategy is discussed.

4.1. Data sources

The dataset for the study is composed of formal written text and informal oral text. Formal text refers to laws and decrees produced by national governmental institutions, such as the Peruvian Ministry of education. Informal texts consist of interviews conducted with key informants in relation to their experience with the Peruvian education system.

4.2. Data collection

The collection process of documents was done entirely online and is summarized here. Except from the 1972 “General Education Law”, the following listed norms and/or guidelines remain in force at the present day, as they haven’t been replaced by a latter one. The reason for choosing the 1972’s Law is based on its public philosophy content, that remains as a living legacy for some of the workforce in the Education system. The sources and direct access to the norms listed in this section are specified in the Appendix 1.

Norms related to People with Disabilities in Peru:

- 2001, Peru ratifies with the OAS the Inter-American Convention to Eliminate Discrimination against Disabled Persons.
- 2007, Peru ratifies the Convention on the Rights of Persons with Disabilities. It enters into force in 2008 (International Convention).
- 2012, Second General Law on Persons with Disabilities, published in 2012.
- 2018, Law No. 30832, Law that amends articles of Law 28036, Law for the Promotion and Development of Sports, to potentiate sports talent and ensure the integration of persons with disabilities in the National Sports System.
- 2019, Supreme Decree No. 01-2019-MIMP, Supreme Decree approving the National Plan for Persons with Autism Spectrum Disorder 2019-2021.
- 2021, Supreme Decree No. 007-2021-MIMP approve the National Multisectoral Policy on Disability for the Development to 2030.

Peru National Norms and Guidelines Exclusively Education-Related:

- 1972, Decree Law N° 19326, "General Education Law".
- 2008, Ministerial Resolution N° 0069-ED, "Norms for the enrollment of children and young people with disabilities in the different levels and modalities of the educational system within the framework of Inclusive Education".
- 2016, Ministerial Resolution N° 281/2016. "Approves the National Curriculum for Basic Education."
- 2018, law n° 30797, Law that promotes inclusive education, modifies article 52 and incorporates articles 19-a and 62-a in law 28044, general education law.
- 2020, Supreme Decree N° 009-2020-MINEDU, Supreme Decree approving the "National Education Project - PEN to 2036: The Challenge of Full Citizenship".
- 2021, Supreme Decree N° 007-2021-MINEDU, Supreme Decree amending the

regulations of Law N° 2804, General Education Law, approved by Supreme Decree N° 011-2012-ED.

- 2022, Vice-Ministerial Resolution N° 038-2022-MINEDU "Provisions for the implementation of the intervention to strengthen educational services for students with hearing disabilities or deaf people in Alternative Basic Education Centers".

The Data collection consist also of two in-depth interviews conducted to two young people with disabilities, whose impairments were developed or acquired from a very early age. They both experienced regular school, while only one of them in addition experienced special school during a short period of time. They have in common being now women actively involved in activism for the visibility of people with disabilities, artists, and social communicators. Their activism and work are particularly relevant as they are both motivated by their own experience of living with a disability. This tentatively provides a common ground of long-time process of self-reflection about their educational experience as well. Their educational experiences are relevant for the research design as in them has been kept registered educational policy practices that had a differentiated interaction with their embodied impairments, as well as specific institutionalized practices targeting people with disabilities.

The list of interviews that was analyzed are as follows:

- Interview N°1. Interview made to an adult in its late 20's, self-identified as both, a person with a functional diversity and a person with disabilities. The interviewee is a Peruvian citizen, who studied in Regular School. She's currently a Japanese Language Student before attempting to enroll a postgraduate program. She lives in Japan and has been granted a full scholarship. She uses as a mean for transportation an electric wheelchair provided by her scholarship since her arrival to Japan, due to the different conditions her body is not prepared to deal with. The interview was made in person, in the dorm where she lives. Her original name has been changed to Mayumi.

  - Date of the interview: May 24th, 2023.
  - Duration of the interview: Approximately 1 hour.
  - Language in which the interview was conducted: Spanish.

- Interview N°2. Interview made to an adult in its late 20's. The interviewee is a Peruvian citizen, who made studied in both Special and Regular School. She's currently living and working from home, in Peru. She had low-vision during her time as a student but progressively lost her vision. The interview was made by zoom without video recording as it was requested by her. Her original name has been changed to Hikari.
  - Date of the interview: June 11th, 2023.
  - Duration of the interview: Approximately 1 hour and a half.
  - Language in which the interview was conducted: Spanish.

As an additional note, it should be specified that all texts were produced in Spanish. Terms and names of categories have been elaborated in Spanish and later translated to English by the author. Extracts from the sources utilized for the current paper were also translated by the author, who is a native Spanish speaker, with an emphasis on meaning over accuracy.

4.3. Data analysis

Both formal and informal texts were analyzed using a discourse analysis technique. Discourse analysis is an interpretative technique and involves identifying the meaning of words and messages by means of understanding the way they are used in the text's argumentative strategy. The analysis required preparing questions as guidance. Some questions were prepared as reference, but the actual process was done in a non-structured way. Reference questions are reworked and simplified from the guide proposed by Joe (Joe, 2013). The defined questions for the analysis were:

- From what position is the policy elaborated?
- What antecedents does the policy define?
- How is the present situation and the desired future constructed through the policy's narrative?
- What are the causes of the defined public problem that the policy solves?
- How are the solutions solving the defined public problems?
- What elements compose the defense strategy for the policy?
- What elements are explicit and implicit?
- What actors and terms are present or omitted?
- What relationships are defined between the key terminology used by the authors of the policy?
- How is evidence for the policy defined and used?

Results of the analysis will be presented and discussed simultaneously in the same section to facilitate argumentation.

Chapter 5: Research findings and discussion

5.1. About the underlying logic of the organization of the educational offer and the assessment of equality/inequality in the norms and institutionalization of education policies for children and young people with disabilities.

From a regulatory dimension, schooling in Peru did not have a norm that indicated the problems to which education would be responding, the principles of the educational system neither how all forms of education already existing should be organized, until The Educational Reform of 1972. According to the chronology published on the website of the Peruvian Ministry of Education (Perú. Ministerio de Educación. (2020, October 31)), the first ***General Education Law*** was published in that year, through which Special Education was also ordered for the first time. This law is significantly influenced by the discourse of "Social Justice" as it recognizes the role of community organization as a legitimate form of transmission and provision of non-formal education, as well as the role of education as a tool for humanistic transformation. The compulsory nature of Basic Education and the free education provided by the State are also established as principles. These will be principles that will henceforth mark the expectations regarding schooling in Peru.

It is also the first time that a conceptualization of "Special Education" is regulated and ordered official. It establishes that this form of education is intended for students who have an exceptional situation, ordered by a classification that groups these situations with the influence of the medical-rehabilitation discourse: "*mental deficiency, hearing and language problems, blindness and subnormal vision, physical limitations and impairments, behavioral disorders and significant emotional disturbances and social irregularity*". It also mentions gifted students, who are determined to have an "exceptional condition," yet would not be integrated into "Special Education." The treatment that students with disabilities should receive, according to this norm, is training for their labor insertion, if possible, and if not possible, they would be helped to obtain an education and rehabilitation. Likewise, it would be part of the objective of Special Education, to instruct families and the community so that they also participate in the schooling of the students. It is also determined that students who meet the exceptional conditions described above would attend a Special Education Center, and that the diagnosis of "exceptionality" would be coordinated between the Ministry of Education and the Ministry of Health, and that this service would be offered in the Special Education Centers.

This is perhaps the first time that Peru has sought to align its educational policies with the most progressive ideas on education in the region, such as those of Paulo Freire and John Dewey, in the midst of a period of open hostility from north to south towards governments that sought to restore and/or recognize social rights. However, in terms of education policies for people with disabilities, there was no significant intellectual work in Peru at that time that could provide a compass. Thus, this could explain that its formulation imitated the educational trends of the region.

This development would be interrupted after a few years by the turn towards a new coup d’état in 1975, that will reinstate the still resourceful oligarchic and conservative order. The following decade would be characterized by pronounced impoverishment of the living conditions and civil violence, which would pave the way for the domination of the neoliberal discourse and the curtailment of social rights for at least two decades. The brief explanation of this period is relevant because, on the one hand, there will coexist a generation of educators who would be the subject of consultation as workforce in later decades for the elaboration of educational policies, but on the other hand, a society and political class that will be little reactive to educational problems beyond the interest in economic competitiveness.

The reflection on inequality of opportunities as part of the elaboration of educational policies will lose weight in the following decades due to the hostile and highly politicized conditions that will characterize the normality of sociability in Peru. The Internal Armed Conflict, due to the characteristics in which it emerges in 1980, where the racial/ethnic component will be the object of stigmatization and violence both by the State and by the subversive and terrorist organization "Partido Comunista Peruano-Sendero Luminoso" [Peruvian Communist Party-Shining Path] (PCP-SL) (Peru. Truth and Reconciliation Commission, 2003).

The impoverishment of living conditions, hyperinflation, political violence, added to the debts acquired by the Peruvian State during the 90's with institutions such as the International Monetary Fund-IMF, the World Bank-WB, and the Inter-American Development Bank-IADB, led Peru to subscribe to a double dynamic with respect to public policies, including educational policies. First, to reduce the State's regulatory powers and capacities with respect to private education, and on the other hand, to participate in international commitments and agreements that were aligned with the human development index concept/unit of measure, including those initiatives of UNESCO and the Organization of the American States-OAS. These exocentric pressures emerged in the 1990s. The first law for people with disabilities will not see the light of day until the beginning of the 21st century, while in terms of educational policies, the principle of access to education will become the most decisive budgetary maxim in the Education sector. The construction of public schools in rural and semi-rural areas will become a priority objective, and the measure of school attendance will stand out above other variables in the self-evaluation of the sector's performance. Literacy programs will significantly reduce educational exclusion, but will not solve social marginalization, since educational quality will not yet be a criterion subject to international pressure.

In the 21st century, the Peruvian State began a process of transition towards democracy, seriously damaged by a decade of authoritarian regime and the disappearance of independent institutions that sought to oversee access to basic citizen rights. From this period, not only in educational policy but in public policy in general, an attachment to the notion of Social Inclusion and strengthening of civil society began, a process hindered by the lack of institutionality in the State and civil society, and by the absence of political parties in the strictest sense of the word. It is in this context that the Norms and other legal provisions for the Inclusion of the population with disabilities took place, as well as the build-up of a discourse of Inclusion in civil society and in the Education sector.

The first time that the notion of "Inclusive Education" was incorporated in the regulations was in 2008, in reference to the situation of inequality faced by people with disabilities in the education system. This norm must be understood within the context of the participation of the Peruvian State in UNESCO's "Education for all" initiative. Although the discourse of "Education for all" does not exclude the relevance of offering quality schooling experiences for children and youth with disabilities, nor the transforming role of education for the acquisition of other rights, its guidelines are usually reduced operationally to the expansion of the coverage of access to education.

As the phenomena of path dependence has been explain previously, this exocentric pressures in policy institutionalization tends to develop a divergence between upper level and ground level organization. The divergence within the dominant discourse at an inter-governmental level of Educational equity (that underlines the disadvantaged position, regarding possessing a wide spectrum of opportunities, of those deprived from full education benefits), and the untended reductionism of increasing coverage (understood as the policy practice of enrolling children to an education program, as much as it can be achieved within the possibilities of each learning institution) can be explained as an heuristic conceptualization of “Inclusion”. Furthermore, this instinct elaboration can be supported by the likelihood of picking within the non-unidimensional concept of inclusive education, a one-dimensional understanding of the idea of integrating students with disabilities into mainstream schools. That is why the spirit of the 2008 norm in Peru points out the procedures to order the transition of learners with disabilities from special schools to regular schools, theoretically formally creating the conditions for such transition while putting more weight on the enrolling procedures.

2012 marks a milestone on the introduction of the idea of disability as the existence of "barriers" that exist outside of people with disabilities. Barriers, however, are going to be mainly associated by people with the notion of "accessibility" of infrastructure. The publication of a New Basic Education Curriculum in 2016, in parallel, is going to continue developing ideas around the concept of Inclusion, betting on a broad notion that not only contemplates people with disabilities. The National Curriculum introduces the idea of a series of ethical principles that should be transversal to learning in any of its forms and levels. Among these principles, which it calls "transversal approaches", it includes "Inclusion and Attention to Diversity". According to the Curriculum, diversity is a condition of the classroom, since there are several variables that cause a heterogeneity of ways of being and doing to be expressed, such as "sex/gender, ethnicity, religion, disability, learning rhythms, among others". In other words, an idea is introduced that, although it is simply explained, contains an epistemological background that is difficult to internalize and, therefore, subject to the use of "formulas" in order to put it into practice. What will end up being understood is rather the cultivation of tolerance for difference.

Changes are also taking place progressively in the field of language. Among public education teachers, the term "inclusive students" is being consolidated to refer to students with disabilities, although with reservations about referring to their peculiarity as a disability. During this time, the dissemination of the condition of autism among children is also taking place. An awareness campaign by associations that promote the protection of children and young people with autism also has an influence on the educational field, and then the hesitation arises as to whether or not a condition such as autism should be equated to a disability, which has a negative connotation. It is for this reason, perhaps, that the term "inclusive learners" is a somewhat employed resource since this condition is the one that seems to be most common, along with other conditions involving cognitive and relational skills, in regular schools, and at the same time, the one that seems to present the most common challenges for classroom teachers. Meanwhile, changes in regulatory provisions begin to consolidate the place of students with more obvious disabilities, i.e., in official terms, with severe disabilities, are the Special Schools, which are known as "CEBE", an abbreviation for "Centros de Educación Básica Especial" (Special Basic Education Centers). This situation is also driving a growing demand for diagnostics so that parents can request for their children one of the two places per classroom that the Ministry of Education also mandates schools to enforce.

In 2018, the officialization of "Inclusive Education" begins within the General Education Law. The next step, which would be, within the legal discourse, the incorporation of the definitions of all the elements that lead to put it into practice would have to wait a few more years, until 2021. The norm that regulates how Inclusive Education is implemented is the most ambitious exercise of assembling a regulatory discourse on educational policy that seeks to have internal coherence. However, in such assembly, more than one discourse acting on students with disabilities can be distinguished. On the one hand, there is the general principle of Inclusive Education, which is not exclusively relevant to students with disabilities but instead it enlarges its scope by targeting different sources of the learner's diversity as given by "age, gender, health condition, social and environmental risk, poverty, ethnicity, culture, native language, linguistic diversity, talent and giftedness, disability, learning disorders, affected by violence, etc".

Concerning further conceptualization, It specifies the measures to be taken to ensure Inclusive Education, such as the setting mechanisms to identify educational barriers and, thus, adapting the environment. However, an exceptional treatment persists for the case of students with severe disabilities, for whom a "Special Basic Education" is applied, which is provided in institutions that have that specific purpose. One of the purposes of this service is "to identify and reduce the risk of acquiring a disability or that it becomes more severe". This characterization of the service may be reasonable in a pragmatic sense as it contains a threat, given the weakness of health care networks to meet the needs of children and youth with disabilities who require it. The use of the educational infrastructure and workforce to substitute the scarcity of health coverage in urban-marginal, rural and semi-rural areas appears as pragmatic arrangement against the highly costly measure of demanding the health sector to provide the requested solutions. However, at the same time, and in practice, it also places limitations on the purposes of education in general that are applied to the rest of the students who do not qualify with these characteristics. More importantly, this divergence in goals expresses mismatching discourses about the role of education, and specifically a circumstantial application of a concept that is framed as a general principle as long as the educational policy doesn't target learners categorized as having “severe disabilities” and “gifted”.

At an analytical level, the proposal of Ideas affecting the policy process could be taken tentatively as an explanatory frame. Two approaches, Ideas as policy solutions, as well as Ideas as problem definitions could be useful for this specific case. The change of the inner organization of the distribution of responsibilities and working domains at a national government level, as well as the subgovernment level, could create inner conflicts and bureaucratic entrapment that could be costly-effective poorly appealing. As a result, keeping the concept of special education but assuring that an inclusive approach would be transversal appears like a formal solution.

5.2. Value orientations institutionalized, and Risks and Discomforts faced by children and youth with disabilities.

Both interviewees are involved in social activism in favor of the visibility of people with disabilities, whom they represent. Both also work in jobs involving artistic creativity and social communication. However, their educational trajectories have been very different due to the characteristics of their disabilities.

5.2.1. Mayumi's case

Mayumi, 28, the first interviewee, was born in the city of Lima, Peru, with a physiological dysfunction that prevented the expected development of her lower limbs. Therefore, from a very early age, her parents sought medical treatment so that she could eventually enjoy a childhood free of health concerns. However, during her growth, her body's response to treatments and interventions was prolonged, and at a certain point new health problems related to her musculoskeletal system appeared, which made her care more complex. Her last medical treatment ended shortly before she finished high school, however, much of her time as a student was spent attending classes.

In her words, she is a person with "functional diversity," referring to a concept she learned during her time in college that helped her accept herself as a whole being, not divided in her identity and her body facing the challenge of reduced mobility. She assures that now that she has been discharged, and although the repercussions in her body are visible, the fact that she can walk and does not have a diagnosis, would make her not ileigible for a certificate of disability in Peru. In Peru, before traveling to Japan to study, she felt she was a fairly functional person. However, once she arrived in Tokyo to live, she realized that her body was not prepared for the challenges of moving in that city, so now she gets around to go to classes and to go for a walk or to the supermarket in an electric chair with which she can access the subway system.

The medical treatment she was undergoing to recover her mobility and the development of her lower limbs required her parents to take her very early, before dawn, to a hospital specializing in the physical rehabilitation of children with disabilities. Therefore, from the beginning of her life as a student, they had to carefully choose a school that met a series of requirements that would ensure that they could come to her aid if she had an accident. This complicated the search for a school that would accept his parents' requests to ensure his well-being, such as being in a first-floor classroom. Eventually they found a public school that seemed committed to Mayumi's welfare, however, there was a period when they could not assign her to a classroom in other place than the second floor, so her parents, in order to keep her familiarity with the school, had to find someone who could carry her up to the classroom and bring her down at the end of class.

At school she says that she could not help but notice that her physical condition was at a disadvantage with respect to her peers, and this significantly influenced her decision to stand out in school for her academic abilities, and thus compensate for what she perceived she lacked. Although she did not perceive herself as having any difficulty relating to other students or teachers, she admits to having been the subject of comments at some point referring to her: she remembers several times being referred as “malita”, and other time being mocked at her back for the way she walked.

In Peru, the term "malita" (it can be translated as "unwell” but adding a suffix at the end of the word that in Spanish can express as much as a patronizing relation with the subject, as a close relationship) refers to not being in good health, but without specifying what ails one, since this condition is one with which others are familiar on a daily basis. In her case, she was "unwell" because she could not move around with the apparent naturalness with which others moved around, and furthermore, because she was restricted in the type of physical activities in which she could engage. She lives inside herself with metal devices that were introduced so that she could correct her movement, posture, and body development, and therefore, she must be careful that they are preserved in harmony with her body. About the time being mocked, she acknowledges that before that time she had not realized that her way of walking wasn’t “not normal”. For her, how she moved is comparison with her peers was unnoticed as she can’t see herself from the outside. Nevertheless, she considers discovering she was a “special child” by far on of the most difficult findings to endure during her time as a school learner. This discovery didn’t take place in the school but by watching a telethon raising fonds for the treatment if children with impairments in the same rehabilitation center she used to attend daily during her childhood. She used to encourage her parents to send money, as she was moved by the pity exploited by the telethon, that openly exposed children, called “special” and their vulnerabilities. Eventually one day she realized that she used to be a patient as those children, and, therefore, also acknowledged as special too. This discovery was brutal for her.

One of the things she was unable to participate in during her time at this school was physical education classes and many of the games that were part of recess time. She also could not go out with her classmates in her free time since she perceived that they would not consider the limitations she had and the care she required. During physical education class, she remained in the classroom talking with her classroom teacher, and in this way she let the time pass. From the moment she entered the school, her parents asked to be excused from the physical education class, as a preventive measure that Mayumi could suffer an accident because she did not have the supervision they considered necessary. There were no objections from the school, nor was there any proposal from the school throughout her elementary school to allow her to do activities adapted to her limitations.

She considers that her experience as a student was not bad, but improved significantly when her parents moved her to a private high school with few students, and which also promoted the Nikkei culture, to which she belonged on her mother's side. This school was relatively far from home, but the benefits far outweighed her parents' misgivings about not being able to have her close to home in case of an accident. At this school she found a sense of community among her classmates that she did not have in elementary school. At this school she was also not subjected to comments or name-calling from students or teachers, feeling free to excel in both her social and academic skills. In addition, during his time at this high school, physical education hours became school hours in which he could do journalism projects or participate in cultural activities. It was the physical education teacher who took the initiative to get her involved so that she could earn her grade in each class.

5.2.2. Hikari's case

The case of 29-year-old Hikari, as previously mentioned, differs from that of Mayumi with respect to the uniqueness of her educational background. Hikari had low vision from a young age. After completing preschool at age 5, her mother sought to enroll her in a special school for the visually impaired. They were able to get her into a private school subsidized by a religious order, a parochial school. The Franciscan order is known to be traditionally involved in providing this type of educational service, and in Lima, Andrea's hometown, they had a school, albeit far from where she lived. She went to the school in a mobility vehicle provided by the school itself, and was a student there for the first 3 years of her primary schooling. In this school she received instruction that was different from that intended for children and young people with blindness. She explains that the teaching methodologies were different and they preferred that children with low vision were not familiarized with learning the Braille method. However, she was instructed in the use of the cane to guide her when walking, and how to locate and move in some types of public spaces, such as the sidewalk, a block, a park, among others. However, she was only able to learn the latter in her third year due to her young age.

She recalls that throughout these three years she became familiar through language with categories such as low vision and blindness. However, despite using materials that had been adapted for people with low vision, she was unaware that outside her school other children her age used different materials and learning methodologies. She also says that in the afternoons she had to have a private teacher who came to her home to complement what she learned at school. After the third year, the school, following regulations that it is not possible to specify whether they were internal or from the Ministry of Education, terminated her stay in Special Education, and her mother had to look for a regular school where she could enroll her.

She says that leaving the special school to join a regular school was never an entirely satisfying experience. The sense of community with which she was familiarized during her first three years of elementary school was not something she was able to replicate later on. Her mother was constantly changing schools as she never found one where she felt Andrea received the quality of attention and commitment from the school that she required. Andrea says that one of the most disconcerting experiences during the rest of her education in regular schools, where she remembers being socially fluent and making friends, was having to be separated during some class hours to a segregated classroom where she and another visually impaired classmate were taught by a teacher who had been trained to work with a methodology that was adapted to her learning needs.

She also recalls that it was very difficult for her mother to find a school for her when she realized that the experience she was receiving did not contribute to Andrea's well-being, since schools were not always willing to accept her. This was especially true in the beginning. The first school her mother found for her when she left the Special School made it a condition that she move down a grade since the teacher who had the methodology necessary to teach students with low vision was not available for her grade level. However, when she entered high school at another school, her mother bought her a computer, having previously taken a course on how to use a text reader, so she found a means by which to access adapted materials and record her notes in class so she could listen to them later.

Despite changing schools several times, she says she maintains some friendships to this day. When asked if she played with other classmates at recess or participated in physical education classes, she assures that she was almost always left out. At recess time she walked alone, and in physical education she did not find a way to integrate nor did they try to integrate her because all the activities were group sports. She regrets that during her time in regular school, the schools where she studied did not bother to provide her with the learning resources she needed. In addition, she believes that the schools, by allowing a student like her to integrate, should be responsible for offering her an inclusive education, that is, providing all the means and resources according to her needs. In contrast, she feels that they admitted her without really caring about her well-being.

Chapter 6: Conclusions

The analysis of the regulations and the interviews conducted shows two narratives of educational policies that should be seen in a complementary way, as both reveal the contradictions between discourses about the educational policy targeting school learners with disabilities in Peru. It is important to contextualize these narratives in the.generalized impoverishment of educational services that Peru has been going through, pronounced the most from the 80's to the end of the 90's. Consenquently, during this period, children and youth with disabilities could have been one of the most affected given their already vulnerable condition. This is reflected in the absence of norms and guidelines regulating education for people with disabilities during this period. The oldest general legal norm that dealt with special education, according to the chronology published by the Ministry of Education, dates back to the early 70's. It is worth noting that it did not follow the same legal framework as that of the 1970s, neither it followed a path of institutionalization of policies targeting students with disabilities,leading eventually to the build-up of consultative, supervisory, sanctioning, or building a policy of inclusion that would be organically assembled with civil society.

Instead, it could be considered that inclusive education policies take more of an imposing form, which should be based on professionals who are familiar with the humanist principles related to the of the right to education, and education as a mean for human development, which were part of the basis of the educational reform of the 1970s. Likewise, the existence of universities of education or faculties of education that integrate in their training programs the specialty of Special Education, must be largely responsible for the ideas that dominated the Special Schools and that were not subject to greater scrutiny by the role in educational policies of the Ministry of Education, and respectively, of the Peruvian State.

Since the 20th century, we can see a formalization in the legal discourse of notions on disability and inclusive education that had already begun to form part of the technocratic language and in the training received by professionals in the education sector due to the relationship between the Peruvian State and bodies such as UNESCO and OAS. However, there are unresolved issues that not even the guidelines of these bodies are able to resolve for the States that seek to implement them. Perhaps the case of Peru is a unique case, since the historical lack of institutionalized bodies with power over political actors in terms of educational policies for children and youth with disabilities seems to have left to the technocracy of the education sector the difficult task of ideologically integrating different trends and incompatible practices without mechanisms for their revision.

Mayumi's experience, as detailed in the analysis, refers to a period in which the discourse on barriers that will distinguish the integrative discourse on disability in the second decade of the twentieth century had not yet been institutionalized. Instead, she is surprised to discover as a young woman that the “special” children who were the objects of her empathy, for whom their living expensens and rehabilitation fees the telethon justified its existence, were also children who shared qualities with her time as a regular patient of the hospital during her childhood. At school she only came to realize that she was not seen as equal when she heard a teasing about how she walked, and when she was called "malita/unwell".

Hikari's experience is very revealing about the mismatch of two systems of education, where schools appear as units isolated from each other and the experience of a student for whom no one is fully accountable for her well-being seems to remain hidden from policy makers. Probably the Special School, but at the time when Andrea attended the first three years of elementary school, had an idea of disability that prioritized the welfare of the student with a disability more than the Regular School.

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Appendix 1: National Norms and Guidelines

A. General Norms about People with Disabilities

Year	Name [Translation]	Name [Original]	Digital resource
2001	Peru ratifies with the OAS the Inter-American Convention to Eliminate Discrimination against Disabled Persons	El Perú ratifica con la OEA La Convención Interamericana para eliminar discriminación contra discapacitados	http://www.oas.org/OASpage/press2002/sp/a%C3%B1o99/a%C3%B1o2001/agosto01/0830-185.htm
2007	Peru ratifies the Convention on the Rights of Persons with Disabilities. It enters into force in 2008	El Perú ratifica La Convención sobre los Derechos de las Personas con Discapacidad. Entra en vigor el 2008. (Convenio Internacional)	https://busquedas.elperuano.pe/normaslegales/entrada-en-vigencia-de-la-convencion-sobre-los-derechos-de-convenio-internacionales-1342819-1/
2010	Law recognizing the Peruvian Sign Language	Ley que reconoce la lengua de señas peruana	
2012	General Law on Persons with Disabilities, published in 2012	Ley General de la Persona con Discapacidad, publicada en el 2012	
2018	Law No. 30832, Law that amends articles of Law 28036, Law for the Promotion and Development of Sports, to potentiate sports talent and ensure the integration of persons with disabilities in the National Sports System	Ley N.° 30832, Ley que modifica artículos de la Ley 28036, Ley de promoción y desarrollo del deporte, para potencializar el talento deportivo y asegurar la integración de las personas con discapacidad en el Sistema Nacional del Deporte	https://www.gob.pe/institucion/conadis/normas-legales/258321-30832
2019	, Supreme Decree No. 01-2019-MIMP, Supreme Decree approving the National Plan for Persons with Autism Spectrum Disorder 2019-2021	Decreto Supremo N.° 01-2019-MIMP, Decreto Supremo que aprueba el Plan Nacional para las Persona con Trastorno del Espectro Autista 2019-2021	https://www.gob.pe/institucion/conadis/normas-legales/258322-01-2019-mimp

2021	Supreme Decree No. 007-2021-MIMP approve the National Multisectoral Policy on Disability for the Development to 2030	Decreto Supremo N° 007-2021-MIMP aprueban la Política Nacional Multisectorial en Discapacidad para el Desarrollo al 2030	https://www.gob.pe/institucion/conadis/informes-publicaciones/1952667-politica-nacional-multisectorial-en-discapacidad-para-el-desarrollo-al-2030

B. Exclusively Education-Related Norms:

Year	Name [Translation]	Name [Original]	Digital resource
1976	Decree Law N° 19326, "General Education Law".	Decreto Ley N° 19326, “Ley general de educación”.	https://www.deperu.com/legislacion/ley-19326-pdf.html
2008	Ministerial Resolution N° 0440-2008-ED, "Approving the National Curricular Design of Regular Basic Education".	Resolución Ministerial N° 0069-ED, “Normas para a matrícula de niños, niñas, jóvenes con discapacidad en los diferentes niveles y modalidades del sistema educativo en el marco de la Educación Inclusiva”	
2016	Ministerial Resolution N° 281/2016. "Approves the National Curriculum for Basic Education."	Resolución Ministerial N° 281/2016. “Aprueba el Currículo Nacional de la Educación Básica”	https://siteal.iiep.unesco.org/bdnp/3107/resolucion-ministerial-ndeg-2812016-aprueba-curriculo-nacional-educacion-basica-resolucion
2018	Ley n°30797, Ley que promueve la educación inclusiva, modifica el artículo 52 e incorpora los artículos 19-a y 62-a en la ley 28044, ley general de educación	Law n°. 30797, Law that promotes inclusive education, modifies article 52 and incorporates articles 19-a and 62-a in law 28044, general education law.	https://busquedas.elperuano.pe/normaslegales/ley-que-promueve-la-educacion-inclusiva-modifica-el-articul-ley-n-30797-1662055-2/
2020	Supreme Decree No. 009-2020-MINEDU, Supreme Decree approving the "National Education Project -	Decreto Supremo Nº 009-2020-MINEDU, Decreto Supremo que aprueba el “Proyecto Educativo	https://bicentenario.gob.pe/pen-2036/

	PEN to 2036: The Challenge of Full Citizenship"	Nacional - PEN al 2036: El Reto de la Ciudadanía Plena”	
2021	Supreme Decree No. 007-2021-MINEDU, Supreme Decree amending the regulations of Law No. 2804, General Education Law, approved by Supreme Decree No. 011-2012-ED	El Decreto Supremo N° 007-2021-MINEDU, Decreto Supremo que modifica el reglamento de la Ley N° 2804, Ley General de Educación, aprobado por Decreto Supremo N° 011-2012-ED	https://www.gob.pe/institucion/minedu/noticias/492288-modifican-reglamento-de-la-ley-general-de-educacion
2022	Vice Ministerial Resolution No. 038-2022-MINEDU "Provisions for the implementation of the intervention to strengthen educational services for students with hearing disabilities or deaf people in Alternative Basic Education Centers"	Resolución Viceministerial N° 038-2022-MINEDU “Disposiciones para la implementación de la intervención de fortalecimiento de los servicios educativos para los estudiantes con discapacidad auditiva o personas sordas en los Centros de Educación Básica Alternativa”	https://www.gob.pe/institucion/minedu/normas-legales/2902930-038-2022-minedu

Appendix 2: Interviews transcripts [translated from Spanish to English]

Interview N°1

INTERVIEWER: Today is May 24, Wednesday. It is 8:38 in the evening and I am currently in the Rikkokai Nipponkai dormitory. We are in a classroom having a conversation. My interviewee is with me. First of all, I want to thank you for agreeing to participate in this conversation, which is more of a conversation than anything else. It's about questions that aim to answer concerns that I have in a research that I'm conducting for my master's degree. And, well, from now on I would like to record the conversation we are going to have. I don't know if you agree, because the purpose of the recording is to be able to record it and then analyze it.

MAYUMI: Yes, I agree.

INTERVIEWER: You agree. Okay. So, do you agree to the interview?

MAYUMI: Yes.

INTERVIEWER: Okay. Thank you very much. If at any point I mention something or ask something that makes you uncomfortable, please let me know so I can rephrase it or move on to another question, and also, if there is any personal information that you would like me not to share after the end of the interview - like for the official record of this interview in the research - at the end we talk about it to remind you of some personal details that you have disclosed and whether or not you would like to withhold or keep them anonymous.

MAYUMI: Yes.

INTERVIEWER: Already? Okay. Then I'm going to give you the microphone. You can place it wherever you want.

MAYUMI: Will it sound good in there? Yes?

INTERVIEWER: Yes.

MAYUMI: Yes.

INTERVIEWER: Okay. So, uh... can you tell me your name or what you want me to call you?

MAYUMI: Yes, I am Mayumi.

INTERVIEWER: [nods].

MAYUMI: What other data do you want?

INTERVIEWER: Uh... What would you like me to call you from now on in the interview?

MAYUMI: MAYUMI:.

INTERVIEWER: MAYUMI:.

MAYUMI: Okay. Yes.

INTERVIEWER: Uh... How old are you?

MAYUMI: I am 28 years old.

INTERVIEWER: 28 years old, and what do you do at the moment?

MAYUMI: At the moment I am a student of Japanese.

INTERVIEWER: Where are you studying?

MAYUMI: I am studying at Shinjuku Nihongo no Gakko.

INTERVIEWER: [nods] And what plans do you have after studying or finishing your Japanese studies?

MAYUMI: Well, my goal being here in Japan is to get a master's degree.

INTERVIEWER: [nods] Where do you come from?

MAYUMI: From Peru.

INTERVIEWER: From Peru.

MAYUMI: From Lima, Peru.

INTERVIEWER: Uh... You were born in Peru?

MAYUMI: Yes.

INTERVIEWER: [nods] And... I wanted to ask you another question. Uh... before coming to Peru, sorry, before coming to Japan....

MAYUMI: [laughs discreetly]

INTERVIEWER: ...did you have any other occupation?

MAYUMI: Yes, I am an audiovisual communicator by profession.

INTERVIEWER: [nods].

MAYUMI: And I've dedicated myself to film directing and... well, independently to film directing, to being a visual artist and I've also worked in different companies in the press sector, education and issues related to social transformation.

INTERVIEWER: [nods] And if a person would want - who doesn't know you - would want to know more about you, who you are, who **MAYUMI:** is, uh... what would you choose to say about yourself to that person?

MAYUMI: What... in a word or...?

INTERVIEWER: As many words as you want, as long as you need.

MAYUMI: How would I describe myself?

INTERVIEWER: What could you say about yourself so that person would have some idea about who you are?

MAYUMI: Uh... Well, it depends, I think, on the context I'm in, because if I'm in a more professional context I think my studies and that would be the first thing I would reveal.

INTERVIEWER: [nods].

MAYUMI: Eh... but if not, I don't know. It's really hard for me to describe myself, I think.

INTERVIEWER: [nods].

MAYUMI: Yes. I would rather... I always prefer to talk to people and let them get to know me.

INTERVIEWER: [nods] And is there anything in particular that makes you uncomfortable that they ask about you or want to know about you?

MAYUMI: Uh... Not really. I'm a person that I think I'd rather be asked than they're assuming or kind of creating this...stories, right, about me. So yeah, yeah, I'm always up for conversation as long as it's in a respectful way where it comes from, right, the question, yeah.

INTERVIEWER: Well, uh... So, **MAYUMI:**, since you told us that you don't really have a problem with the questions, as long as they are well done, then I will try to feel as open and free as possible [laughs] to....

MAYUMI: That's good [laughs].

INTERVIEWER: ...ask whatever questions I want, as long as I maintain a respectful relationship with you, right?

MAYUMI: [nods].

INTERVIEWER: Uh... Where have you lived most of your life?

MAYUMI: In Lima, always.

INTERVIEWER: In Lima.

MAYUMI: Yes.

INTERVIEWER: Uh... How would you describe the place where you live?

MAYUMI: Eh... Well, it is a small district. I feel that lately in Lima there are like these... big... big buildings and condominiums and they have lost a little bit of what was the... this neighborhood culture, right, and where I lived that still remains, right? It was... my house all my life has also been my mother's house all my life, because it was my grandparents' house. I lived with my grandparents and with my parents too. So I have very nice memories of having grown up in a very familiar environment, not only because of the family that lived in my house, but also because of the neighbors and everything, who already knew each other from generations before me... before mine, right?

INTERVIEWER: [nods] So your whole childhood, your whole adolescence and also your, well, adulthood....

MAYUMI: Yes.

INTERVIEWER: ... you've been to that same place.

MAYUMI: That same place, yes. Right.

INTERVIEWER: Uh... Where did you go to school?

MAYUMI: Eh... My studies since I was a beginner were done in a nest that was close by, just a few blocks away.

INTERVIEWER: [nods].

MAYUMI: Uh... because it was a small nest and because it was close to my house, right? And because since I was three months old I had been doing daily therapy at San Juan de Dios. So this nest, being small and close by, gave me the license to miss a day or two to go to therapy, right?

INTERVIEWER: [nods].

MAYUMI: That was during I think the... the first year and a half or so that I was in the nest - because I entered when I was two years old- and after that... three, four and five years I was totally in the nest, right?

INTERVIEWER: And how long did it take from your home to the place where you did therapy?

MAYUMI: Ugh... a lot. We were leaving about before 5 o'clock in the morning, I think, yeah, when the sun wasn't up yet.

INTERVIEWER: [nods] Did you take those trips as a child with your parents?

MAYUMI: One question, Vilma, have you seen the documentary?

INTERVIEWER: [says something that is not audible].

MAYUMI: Oh yeah [laughs]. Ya, ok. Yeah, yeah, yeah, yeah, with my dad and mom.

INTERVIEWER: When was the last time you were in a classroom?

MAYUMI: Yesterday? I mean, from Japanese or in what sense?

INTERVIEWER: In Peru.

MAYUMI: Well, when I finished college.

INTERVIEWER: [nods].

MAYUMI: That was in the year two thousand and ten... ah... as a student...

INTERVIEWER: Yes.

MAYUMI: Yes. As a student in 2018.

INTERVIEWER: So you started at about two years old and... this time it was your return to a classroom after several years.

MAYUMI: As a student.

INTERVIEWER: As a student.

MAYUMI: Yes.

INTERVIEWER: And that clarification is because you have also been in another condition in a classroom.

MAYUMI: Yes, as a pre-teacher as well.

INTERVIEWER: As a pre-teacher.

MAYUMI: [nods].

INTERVIEWER: In college?

MAYUMI: Yes.

INTERVIEWER: Uh... Going back, way back, you say you started pre-school, the... well, kindergarten, what's the name you remember?

MAYUMI: Well, we used to call it a nest, but...

INTERVIEWER: Nest.

MAYUMI: Yes.

INTERVIEWER: When you started the nest, you were two years old?

MAYUMI: Yes.

INTERVIEWER: Uh... but your memories more or less... uh... your memories about the nest, your childhood, more or less since when...?

MAYUMI: I remember a lot. I even remember going to therapy when I was a year and a half old. So, yes... not everything, but I do have very nice memories of that stage.

INTERVIEWER: [nods] During the nest, when you were... since you remember several things from that age, from that stage, uh... did you feel welcome?

MAYUMI: Yes, yes. My parents also; I think they made a great effort to find a place where I could feel fulfilled, right? So I came from another place, that is, from San Juan de Dios, from having done therapy since I was three months old, so I was very conditioned by my as... by what I had physically, right, like having to exercise to heal myself, to be normal, and in the nest I didn't feel that difference or that... that label that was very marked in the previous space.

INTERVIEWER: [nods] In the nest, would you say it was a label-free place?

MAYUMI: Yes, yes. The truth is, I mean, it was... because it was a very small place, with very few students, there was a culture of respect, I think, from a very young age we were always taught that. And so much so that to this day I still maintain many friendships that I made when I was in the nest.

INTERVIEWER: [nods] You say then that you felt full.

MAYUMI: Yes.

INTERVIEWER: Is it a word that you would choose among several? More than others?

MAYUMI: Yes, that's the one that comes to mind now.

INTERVIEWER: ... compared to the... to the place of rehabilitation.

MAYUMI: [nods] Yes.

INTERVIEWER: And when you completed the nest, what was it at how many years old?

MAYUMI: Six. That is, five. She had already turned six a few months ago.

INTERVIEWER: [nods] You moved to another location to attend the [not understood].

MAYUMI: Yes, yes, and that was a big change, because the requirement was, let's say, that it also had to be in the same district where I lived. And all the elementary schools were very big, I mean, they were like... because my nest was small; so it was only one floor, right? On the other hand, this was one of those big schools and they were not willing to make certain concessions. Because I, let's say, when I was in my nest stage, I had a childhood in which I was able to do all the physical activities, but months before finishing my nest I had an accident, I had a fall. And that meant that, from that moment on, like, I was exempted, let's say, for fear of something happening to me, from the Physical Education and Dance course and all these things. So I had to look for a space where they would allow me, or rather, not force me to take these types of courses, right? So, most of... And, well, another condition my parents had was that the school could not be religious. They didn't want it to be this school, which they say was for nuns, and there were many schools like that. So that was not... they were not considering that option. So the only option that more or less adapted and that was going to change even the space so that I could be in a first level and everything was a national school.

INTERVIEWER: [nods].

MAYUMI: And I had come out of a nest... My parents have... they're middle class, right? So they made a great effort to put me in this nest which was not cheap and also... that's something I noticed many years later, right, that I studied with people who had much more economic access. So, moving from that space to a national school, where there were other realities, was something that generated a shock, wasn't it? yes.

INTERVIEWER: Was this condition of being in the same district for reasons of proximity?

MAYUMI: Sure, in case something happened, right?

INTERVIEWER: [nods] And you say that... did your parents tell you how many schools they came to visit to...?

MAYUMI: Uh... I don't really know.

INTERVIEWER: [nods] And did you finally get into that school?

MAYUMI: Yes, yes.

INTERVIEWER: What is the name of the school?

MAYUMI: (Anonymous)

INTERVIEWER: Eh... You mentioned some things that you say were concessions made by the school, for example, that you studied on the second floor, that you were exempted from the Physical Education course and also from other types of workshops or courses, right, that had to do with movement?

MAYUMI: [nods].

INTERVIEWER: And what other types of concessions also...?

MAYUMI: Well, only those really. But for example that second floor issue was not fulfilled in the whole elementary school, right? In the last few years we were moved to the third floor.

INTERVIEWER: [nods].

MAYUMI: So I had to... My mom asked a neighbor to carry me up the three floors, because when I was in fifth grade I had an operation, my first operation, so I was convalescent, I couldn't go up the three floors. So I was convalescent, I couldn't go up the three floors, so I don't know why it was very difficult... I think the board had also changed, so that made them refuse to move us to my classroom, to the second floor, right, yes.

INTERVIEWER: And being carried, what was that experience like, being carried to the third floor?

MAYUMI: [laughs] Well, I've always been small, so I don't weigh anything. But it is a little strange for me... sometimes... like... I think I have learned nowadays to ask for help when I need it and I don't have any problem in being carried, right? But, let's say, I didn't have the option to decide, did I? It was the right thing to do, wasn't it?

INTERVIEWER: [nods].

MAYUMI: So... yes.

INTERVIEWER: Your teachers... you don't remember them putting any impediments or anything that hindered you from getting to class? There was nothing wrong with them carrying you.

MAYUMI: No, no. But, of course, I mean, it was also a bit limiting because I would go up to the third floor, I mean, they would leave me there in the morning and I would stay there all day. So I could not even go to the bathroom, because there was no bathroom on the third floor, right? And I couldn't even go out to see some activity or go shopping at the kiosk, because I was like Rapunzel, like there, this... without... limited, right?

INTERVIEWER: [nods] And do you recall if you ever had teachers who were uneasy about you having to spend your days at school like that?

MAYUMI: Eh... What I do remember is that... Since I was a little girl, since I lived with my grandparents and also with my parents, but, let's say, I spent most of the time with my grandmother, with my grandfather, so I always liked to talk with older people, since I was a little girl. I mean, it was like my grandparents with my great uncles and my great aunts and uncles and me talking there too, right? So I think that... in these spaces of Physical Education for example, where everybody went out to do the activity and I stayed talking in the classroom, I stayed talking to the teacher, and the teacher told me about her life, her marriage, her problems, right? [laughs]. So it was kind of interesting because I was what... seven, eight years old and I was talking to a teacher in her forties, right, about her life? So yes, maybe that was the way to accompany me and I think that in the long run it has given me certain interpersonal tools, hasn't it, to talk to people like that, older people?

INTERVIEWER: And was it always that way the...dealing with the PE class? Was it always written off?

MAYUMI: In that school?

INTERVIEWER: In that school.

MAYUMI: At that school, yes.

INTERVIEWER: [nods] Did they ever propose anything to your parents so that you could do something in that class without it being something...?

MAYUMI: To participate in the class somehow, no.

INTERVIEWER: You had not been proposed.

MAYUMI: No, they never proposed it. It's also, I mean, it's the truth, isn't it, the education in that school, being a public education, it's not that, let's say, the Physical Education teacher or... really did the activity. I mean, it was like the class was there and they had to do it and it was "go around and play soccer", right? So it wasn't really a training with a theoretical basis, let's say, right? So it was like... I don't think they had the curriculum, let's say, to be able to adapt it to me and neither... maybe even... I mean, the Physical Education teacher was very good and everything because she also lived near my house, but there was never that opportunity to "ah, suddenly you can like... participate", was there? No. It wasn't something that was talked about back then, I think.

INTERVIEWER: [nods] And within the things that you were able to do in school, did you ever feel out of place in that school?

MAYUMI: I mean, all my life I have been first place. Then later I understood, right, that it was also my way of compensating in a certain way, right? Like "ah... I can't do this, but then I'm going to make a lot of effort in this other thing", right, which in the long run is not healthy either. But, let's say, I was always... because every year I received, well, the diploma, the medals and what do I know... or there were contests and I also won them. So that was like my... like my label, wasn't it? The chancona of the salon. Yes.

INTERVIEWER: That's what they called you....

MAYUMI: No, no, no [laughs]. But... no, they didn't call me that. But, let's say, it was like...that position I always...I was striving to have it myself.

INTERVIEWER: Let's say you were always aiming for that.

MAYUMI: Yeah. I mean, I must also uh... like confess to you that I didn't have a hard time because my nest prepared me very well. And not only that, but I, when I was four years old, I was bored for example in the nest class. So I told my mom "I want to learn to read". So my mom hired me the teacher who taught the year before, because when they told her... they asked her... like... mom said to the teacher "my daughter is bored. Can't you teach her something else?" And she said "no, but it doesn't say here that I have to teach you this this year", right? So my mother paid for my private lessons. So when I was four years old I was already reading and writing. Then, when there were announcements, I would read the announcement before, before my parents saw it, and I would read it to my friends, right?

INTERVIEWER: [laughs].

MAYUMI: So... And that's why, when I entered elementary school, nobody knew how to read or write. So I spent the first year like that, right? And so, like... I think that helped me a lot throughout elementary school. Yes.

INTERVIEWER: And when you say that it was partly a way to compensate for other things that you didn't... I didn't quite hear how you finished the sentence....

MAYUMI: Ah... I don't remember how I finished it. But... I guess it's because... since I couldn't participate in the PE courses, I felt I had to try harder in the ones I could participate in.

INTERVIEWER: Because it was something that was born from you or was it something that was born from somewhere? From someone...

MAYUMI: Eh... It was born from me, because I never had the imposition of having to get good grades and all that. But when I saw that my dad was very happy when I got a diploma or how he liked to show it to the family, then... that created in me an association that my value was defined by the grades I got, by the awards I got, right?

INTERVIEWER: [nods].

MAYUMI: And, in a way, make them feel that the effort they have made was not in vain.

INTERVIEWER: I mean, so... At the beginning you mentioned, didn't you, that there were things you couldn't do and, in principle, you could apply yourself to this other thing?

MAYUMI: [nods].

INTERVIEWER: That it was having good grades.

MAYUMI: [nods].

INTERVIEWER: Does that mean that, in a way, you did ex... well, you didn't miss, but... you did have the desire to do what your other friends or classmates were doing?

MAYUMI: I mean, for example, in the nest I loved to dance.

INTERVIEWER: [nods].

MAYUMI: I loved dancing. And I...I missed dancing a lot, but it was more the... "no, watch out, something's going to happen to you; watch out, you're going to break something." So, like, "you better not do it," right? So yes, sometimes I felt like I wanted to, but there was always this label, this warning of "be careful with your body; it can be very fragile", right?

INTERVIEWER: And you were also reminded of that in school?

MAYUMI: Uh... Well, it was the order that my family had given to the school, so....

INTERVIEWER: And how did the school... reproduce it? How did you...?

MAYUMI: "Don't do P.E.," right?

INTERVIEWER: Just that.

MAYUMI: Yes, yes.

INTERVIEWER: And when you wanted to play at recess time?

MAYUMI: No. I didn't go out to play volleyball, those things, right? I played like... other things more... tutifruti [laughs], that kind of stuff.

INTERVIEWER: But that limitation, let's say, that you complied with it yourself or someone reminded you of it?

MAYUMI: No, no, no. I knew I could not.

INTERVIEWER: [nods].

MAYUMI: Yes, from the fourth grade on, yes, before I had surgery, I was already in pain too. So it was a... my body itself that stopped me from even wanting to think about the idea of doing something, right?

INTERVIEWER: So you already had the fear inside you.

MAYUMI: Yes.

INTERVIEWER: [nods] So, the teachers, let's say, that in... they only repeated the message of your parents with... only regarding the Physical Education class. Nothing else.

MAYUMI: Yes, yes, yes, yes, yes.

INTERVIEWER: Uh... Do you remember during classes or at school adults referring to you by any terms or any words other than your name when talking about you?

MAYUMI: No, no. Really no.

INTERVIEWER: And when they had to do any... anti... in advance, preparation for the class, do you remember them asking you if there were any problems with the activity or...?

MAYUMI: Uh... We're talking in elementary school, aren't we?

INTERVIEWER: Yes.

MAYUMI: No. I mean, they didn't anticipate anything. For example, what they did warn me about and the teacher called me at home... was that I studied, I don't know if there still are, but at that time there were many strikes, many teachers' strikes. So, since the teacher knew that I was going by car, or for a while I was also going by cab, she would call my house so that I wouldn't go. So she had the deference of warning me, didn't she?

INTERVIEWER: Sure. Yeah, I imagine, all the work it was to go to school for you.

MAYUMI: [nods].

INTERVIEWER: Do you feel that school or elementary school was a satisfying experience?

MAYUMI: Uh... Not really [laughs].

INTERVIEWER: Why, what was missing or what didn't happen?

MAYUMI: Eh... I mean, I did feel, let's say, very limited by... by this... maybe lack of initiative to want to integrate, to get involved in some way. And also that it was a space where there was not the same culture of respect of the nest where I had come from, right?

INTERVIEWER: [nods].

MAYUMI: So, uh... it was a little bit, there were times when I felt that the children didn't understand, that is, this... of assuming what I had or even making jokes at some point, right?

INTERVIEWER: [nods].

MAYUMI: So yes... I understand that that's not something that comes from the children, but it comes from the way their parents have instilled that in them. But, anyway, it was a... There were moments like... like painful moments in....

INTERVIEWER: And was it something that the school knew about?

MAYUMI: Uh... I guess so... But, I mean, my dad also got very involved there and, like he was also going to talk to the kids, right, that... It was just like... a situation like that of... of a kid that had even kind of repeated a year, that kind of... I guess you can consider it as a case of bullying. And my dad went and talked to him, didn't he, and he never did it again? But, let's say, knowing that even realizing that that could happen to me made me feel like... it made me feel like very vulnerable at the time, didn't it, when it wasn't... it wasn't something I expected.

INTERVIEWER: [nods] At that time, what do you remember was the difficulty that cost you the most in your daily life?

MAYUMI: How so?

INTERVIEWER: In your day-to-day life, what was the most difficult thing for you or what, let's say, uh... what overwhelmed you the most in your day-to-day life - things you had to do in getting ready for school, for...?

MAYUMI: Uh... I feel that in that school I never felt a real sense of belonging. Yes. So yeah: it wasn't something that I longed for, like going, right?

INTERVIEWER: [nods].

MAYUMI: I did have a couple of good friends, at least I have them on social networks, but it's not like we maintained communication, right, so I didn't feel... And I was still connecting with my other... with my friends from the previous nest always. So I didn't feel like I had found myself completely, right? Because what I'm telling you, that I played tutifruti, that... it was inevitable sometimes in elementary school that the girls simply wanted to go and play jump rope.

INTERVIEWER: [nods].

MAYUMI: So not being able to participate also kind of made me feel like I wasn't part of, right?

INTERVIEWER: And what things did the other children assume about you?

MAYUMI: I don't know [laughs].

INTERVIEWER: Or what things made you feel, as you say, experiences that you remember having... that were painful...?

MAYUMI: [nods].

INTERVIEWER: What is it that was painful?

MAYUMI: Uh... I mean, like making fun of me, for example, right?

INTERVIEWER: [nods].

MAYUMI: That kind of thing.

INTERVIEWER: Oh, I mean, they never asked you...?

MAYUMI: No, no, no, no, no. But, I don't know... it was a bit strange, wasn't it, because also... I don't know if the teachers also have to do there, but, let's say, they always used me as an example, not because "look, he has this and he does this", but like... "lend me your notebook. So they have to do this, right? And why don't they do these things?", right? Those kinds of situations that I guess could generate also like certain... certain not very nice emotions. So their way of... feeling better was to attack my weak point in quotation marks, right?

INTERVIEWER: And the teachers did ask you what was wrong with you?

MAYUMI: Yes, they did know. Yes they were aware.

INTERVIEWER: But they knew... How did they find out?

MAYUMI: Uh... I mean, when I came, let's say, with this... with the initial diagnosis that I had and then it got complicated, then I also had to have the operation in fifth grade. So they were always aware of "ah, you have to go and have like this operation and you have to rest". I had medical rest also like... because I was in a cast for about three months, so it was three months without going to school too.

INTERVIEWER: Could you mention what that diagnosis was?

MAYUMI: Yes. Uh... it was... At the time when I was born, they found that one of my knees could not be fully stretched.

INTERVIEWER: [nods].

MAYUMI: So, they said, "Oh, he has to do therapy and then he will stretch. But, no matter how much therapy they did, he was like... he didn't want to stretch. So the position of walking with a bent limb... uh... not bent, but like... uh... not straight, made him start to... the hip start to lift as well, that is, the opposite hip, because it was the right knee and the opposite hip. And that was due to a scoliosis later on. So, when I was ten years old, I had an operation on my hip to try to lower it, but it was in San Juan de Dios and the operation did not go well. It was like uf... terrible, super traumatic. They put some pins in me for three months and then they took them out, like this... they were alive; I could see the... the... a hole in my leg and I could see the iron bars going through me and no, no... that was not the right thing to do, but they did it and they didn't do it right. Then, after that, when I was in high school, I started to develop this scoliosis that, just as it caught me at puberty, and I started to grow, it advanced faster too, because the body grows and the spine grew sideways. So, I know -I am getting ahead of myself, am I not? -, but my health was already damaged, because I could not breathe well and my heart was also being pressured.

INTERVIEWER: Sure.

MAYUMI: Then I had to undergo surgery on my spine. And then after college I had the first surgery, which was on my knee.

INTERVIEWER: So it's been a... like a snowball.

MAYUMI: Yes.

INTERVIEWER: [nods] So it's been different experiences growing up.

MAYUMI: [nods].

INTERVIEWER: And how did you experience this change in your body? Because for a moment the challenge was one thing, then the challenge was another. How did you feel your body? Did you feel that the problem was changing all the time or did you feel that it was part of the same thing?

MAYUMI: That's something that I've just been able to kind of... realize now, that since I was very young, that's why I'm telling you that I tried to compensate with grades and everything... I believe in duality. One thing is me and my head and my heart, and another thing is my body. So, seeing my body as alien, like creating a distance between me and my body, was my way of defending myself from these changes I had.

INTERVIEWER: And classmates, classmates at school, do you perceive that they made you notice things about your body that you didn't pay much attention to or did you already...?

MAYUMI: No. Yes, I, for example, I didn't know how I walk. And until now I don't know how I walk, actually. It also depends if I'm tired or not, right? But they did like make me notice that, didn't they? It was "oh... really?", right?

INTERVIEWER: And no one else... But you didn't notice anything different from your classmates? You didn't notice anything particular about them?

MAYUMI: [laughs] No, not really.

INTERVIEWER: But they did notice something different about you.

MAYUMI: Sure, yes.

INTERVIEWER: And did the teachers ever make any, I don't know, any comments to you?

MAYUMI: Are we still talking about elementary school?

INTERVIEWER: Uh... If you want, we can talk about high school, because you already mentioned it.

MAYUMI: [nods] Yes. I mean, in high school the... the approach, let's say, to me changed a lot, because it was a different school.

INTERVIEWER: Oh, okay. It was another school.

MAYUMI: It was another school. They changed me...

INTERVIEWER: So, we'd better finish with the elementary school one [laughs].

MAYUMI: [laughs] Ok.

INTERVIEWER: And, tell me, during that time when you were in elementary school, was the word disability ever part of your memories?

MAYUMI: Never. Never. I mean, the only thing that... I didn't even recognize that word, really, because... For example, in elementary school, I was very excited about helping the Telethon, right? And it was like this: "helping the children who need it most". And they repeated: "to the neediest children". So it's like a... a euphemism, isn't it, of what they really want to transmit; and they don't even use the right words. So, what I liked when I watched the Telethon on TV was to see my therapists.

INTERVIEWER: Could you first briefly tell us what the Telethon is?

MAYUMI: Yes. The Telethon is a... an event that is done on television and that in Peru served to raise funds during a weekend for the Hogar-Clínica San Juan de Dios, which is where I did my therapy, which is a place, now I don't think so, but at that time it was a rehabilitation center for children with physical disabilities.

INTERVIEWER: [nods] But back then you didn't....

MAYUMI: It's just that they never mentioned that word.

INTERVIEWER: [nods].

MAYUMI: They did not mention the word disability.

INTERVIEWER: And what words do you remember them mentioning?

MAYUMI: "Children most in need".

INTERVIEWER: Most needy children.

MAYUMI: Yes.

INTERVIEWER: Oh, that's what you mean.

MAYUMI: Yes, yes. So, I didn't make the connection that, in their terms, I was a more needy child, right, because my parents always paid for everything at San Juan de Dios. Everybody pays for everything. That is not... The fact that it is free, that is, it is not that the money used in the Telethon is going to be used to give them free service, which would be ideal, right? So, I liked to see because I saw the spaces where I had done therapy and I saw my doctors and the therapists, right? And I didn't make the connection that those kids were seen as I might have been seen, right? Eh... Until, for example, there was a mom... a date, that I remember very well, that I was watching the Telethon, and also something that happens is that the people who host this program are actors, they are people from television who are not trained in these issues and are dealing with children...

INTERVIEWER: [nods].

MAYUMI: I mean, it's like... there are many sensitivities there that they are not prepared for. So I remember perfectly... a very well known hostess in Peru who was interviewing the family and a girl... and it is also the fact of wanting to make people donate money through pity.

INTERVIEWER: [nods].

MAYUMI: No? So, I remember this little girl, she made her stand up and said "walk". And the girl, I don't remember if she was using crutches or had a brace on her legs, the thing is that she was walking with a lot of difficulty. And then this TV host said to her, "You see how she can't walk well? That's why you have to donate to the Telethon. Call now to I don't know what...". So, I remember that that marked me a lot because....

INTERVIEWER: How old were you?

MAYUMI: Uh... Eleven, I guess.

INTERVIEWER: You were still in elementary school.

MAYUMI: Yeah. And I had just gone through this process of the first operation too, of relearning how to walk. So it was like "oh...this is how they see us?", right? Yes.

INTERVIEWER: But weren't those kinds of words typical of the school?

MAYUMI: No.

INTERVIEWER: Not that.

MAYUMI: No, no.

INTERVIEWER: Nothing like that either?

MAYUMI: No.

INTERVIEWER: And do you remember or are you familiar with the word "special needs" from your time in school?

MAYUMI: No, neither. No.

INTERVIEWER: Do you remember when was the first time you heard it?

MAYUMI: Eh... Much later, but I think they used it more to refer, for example, to people with down syndrome or with other types of disabilities more related to intellectual and mental disabilities.

INTERVIEWER: And alluding to your diagnosis, did they refer to it in any way at school?

MAYUMI: No, no, no, no, no.

INTERVIEWER: And do you ever remember the word "disease"?

MAYUMI: Uh... yes.

INTERVIEWER: In what contexts, for example?

MAYUMI: Uh... In believing that what I had was a disease, you mean?

INTERVIEWER: Did they mention your illness at school or implicitly all of a sudden, not necessarily mentioning it, but referring to it?

MAYUMI: Maybe to make a difference that I had things I couldn't do?

INTERVIEWER: [nods].

MAYUMI: I don't remember for sure right now, but it could be that they mentioned this "oh yes, she is...". No, enfermita in Peru sounds like something else.

INTERVIEWER: [nods].

MAYUMI: But maybe as bad.

INTERVIEWER: Malita.

MAYUMI: Something like that.

INTERVIEWER: Malita, what would that mean?

MAYUMI: He has a bad leg, something like that, right?

INTERVIEWER: And that... "malita" is like someone who says "do I say it?", but at the same time I don't say it bad.

MAYUMI: [nods].

INTERVIEWER: Right?

MAYUMI: Yes, I mean, it's like these words "cieguito", "cojita", like... by adding the diminutive, let's say, it feels like they take away a negative charge, right?

INTERVIEWER: So you do remember that kind of reference to you?

MAYUMI: Yes, but it wasn't so constan... That wasn't what defined me, let's say.

INTERVIEWER: I didn't define you.

MAYUMI: [nods] In that case "la chancona" was what defined me.

INTERVIEWER: [laughs] And, well, in your transition to high school, what was it like?

MAYUMI: Uh... It just so happened that the school where my cousin studied and where my cousin studied was going to move, which was a school that even when I was in another school, we were always linked to that school, right? It was a Nikkei school. And, previously, that school was located in a somewhat dangerous district and it was also a very big school, that is to say, it had several floors. Then the news came out that they were going to move to another place much more central, much safer and it was only one floor.

INTERVIEWER: [nods].

MAYUMI: So, my parents moved me to that school just to start middle school.

INTERVIEWER: You say it was a nikei school.

MAYUMI: Yes.

INTERVIEWER: What was the name of that school?

MAYUMI: (Anonymous)

INTERVIEWER: Did that school meet the requirement of being in the district?

MAYUMI: I mean, it was originally in La Victoria. Ah... you mean my district.

INTERVIEWER: Yes.

MAYUMI: No, no, not anymore. But there was no... another... So, when we did this... knowing that it was going to be on the second floor, that it was a small school because, as they were about to go bankrupt... the previous year there had been no sixth grade, so all of us who were going to enter the first year of junior high school were going to be new students. So it was, let's say, a bit calmer because we were all going to go through the experience together.

INTERVIEWER: Was it a private school?

MAYUMI: Private, yes. But not expensive. But private.

INTERVIEWER: [nods] In that school you say there were fewer people.

MAYUMI: Yes, there were seven of us.

INTERVIEWER: They complied with the requirement that you were on the second floor?

MAYUMI: Yes.

INTERVIEWER: And you were still exempted from PE class as well?

MAYUMI: In this case, there was a Physical Education course, Folkloric Dance and... it was another one that was like aerobics, like something like that... But here there was this initiative to integrate me, to see how I could be part of it. So, at the beginning, for example, it was... No, in fact, it was all the education... it was this "ok, everybody does their partial - excuse me - bimonthly", right, of the exams, eh... and I had to do a job. For example, the boys played volleyball; and I had to do a paper on what volleyball is and I had to take a test, right? How many players there are, how the rules are, all those things, right? Also with Physical Education and everything... Later on, as the years went by, we saw other ways to earn my grade. Then, for example, with the Physical Education teacher we created a wall newspaper. Then I would interview the kids at school who belonged to some sports team; I would interview them and put it on the wall newspaper. Or some event: I would take the photos and put them on the wall newspaper. Or even former students who had excelled in some sport... I also interviewed them, so... That was cool, wasn't it? And also in Folkloric Dance, for example, the teacher realized that I really liked to speak.

INTERVIEWER: [nods].

MAYUMI: Voice over, isn't it? Voiceover. So, at the events, at... there were theater performances or something... I was in the back, in the booth, and I would do the explanation of what each dance was about, right, and that's how I earned my note.

INTERVIEWER: For events.

MAYUMI: Events, yes.

INTERVIEWER: And during the classes, where were you during the class?

MAYUMI: I used to go out there.

INTERVIEWER: You stayed....

MAYUMI: Except when it was really cold, right? But then I would go out to watch the class.

INTERVIEWER: Oh yeah.

MAYUMI: That's where I took the pictures or... or yes, I mean, I was having fun.

INTERVIEWER: [nods] I mean, they gave you the freedom to do things during that space, in the same place as the others.

MAYUMI: See them, right? Yes, yes, yes, yes. Or take pictures or... yes.

INTERVIEWER: And... how did the dance and physical education teacher treat you?

MAYUMI: Super good vibes... everything, yes... very... I mean, yes, as I said, there was this interest in wanting to integrate me.

INTERVIEWER: [nods] And...could you remind me a little bit about how this stage of high school complements the change that your body had?

MAYUMI: Well, with this difficulty that started to accelerate in my walking, didn't it, that I was getting agitated, because this... the spine was pressing on my heart and my lung? So it was... it was difficult... It was... it was really fast, really. Then, not in the first and second year of high school, but in the third year, when I just like... I reached puberty, let's say, it started to accelerate and that's why in the fourth year of high school I had a surgery.

INTERVIEWER: And you had to be absent?

MAYUMI: I was absent for two months, a whole two-month period. That semester, all the professors in all the courses doubled my grade from the previous semester. Yes, and that was also the applied student, wasn't it?

INTERVIEWER: [nods].

MAYUMI: Not only in the classroom, but for the last three years I was from the whole school.

INTERVIEWER: [nods].

MAYUMI: In my school they did this... like averages of the whole school and I got in the last three years half a scholarship for that.

INTERVIEWER: I mean, let's say that your forte remained in academics, but you also started to do things, like the mural newspaper activities, uh... voice-over narration... as a kind of... as a communicator, right?

MAYUMI: Exactly! Now that... I'm just now realizing it, right? But yes, that... I think it helped a lot later for my profession.

INTERVIEWER: [nods] And was it something that was celebrated or [not understood] by your teachers or your peers?

MAYUMI: Yes, of course. Yes, yes, yes, yes, yes. In that place I felt really good. Yes, because, since the space was small, there was not only a sense of belonging with the people in my class, but also with the whole school. In other words, everyone knew each other. I knew the whole school. We all greeted each other. It was a very nice time.

INTERVIEWER: And how, let's say, this... did school fit in with... You missed some time because of your operation....

MAYUMI: [nods].

INTERVIEWER: But after that recovery there is a rehabilitation process, right?

MAYUMI: In this case, I did not do therapy.

INTERVIEWER: Ah...

MAYUMI: I found out later that I should have.

INTERVIEWER: [nods].

MAYUMI: But the doctor told me "no, you don't need to". That's why I'm suffering now too. But... but yes, I didn't.

INTERVIEWER: Ah ya ya....

MAYUMI: Because it was like "no, that's it", because... I mean, to make a column is like: they put some irons to stretch my back and they said "that's it, that's it. You stand up...". They stopped me on the third day and "there, now you can walk", right? So, anyway, let's say, I was absent because I was hospitalized for about two weeks, right? But from then on they stopped me and yes... Wait, I missed a... No, I didn't miss a two-month period, I missed less, now that I remember. Yes. Oh... I don't remember right now.

INTERVIEWER: [laughs] Don't worry.

MAYUMI: Sorry, I don't remember.

INTERVIEWER: Don't worry.

MAYUMI: But it was a much faster recovery.

INTERVIEWER: And when you went back to school, did you need to use any devices... any help?

MAYUMI: I needed to wear a corset, for example, to keep... because my spine was still very weak, because... I mean, I had... I grew about ten centimeters. So I was not used to my body. So I was... I... I... I was there. And I do remember that there was a day, for example, because my back was very sensitive because I was still under anesthesia and I was just... recovering my sensitivity. Then a friend of mine bumped into me, I mean, because I was sitting... on the side of the passageway and she passed by and I cried, because it hurt me like... a lot, as if she had punched me, but she only touched me. And it felt super bad, like... "forgive me", right? So this... I clearly remember that. But that's all there was to it.

INTERVIEWER: And at this stage in your school, in high school, could you say that your classmates knew that you had?

MAYUMI: Yes, of course. Yes, yes, yes, yes, because they were with me during the process. I mean, even I had to be absent... This was a very complex operation; they didn't know if I was going to come out alive or not.

INTERVIEWER: [nods].

MAYUMI: So, I had to be absent. That's why I lost a little more time too, because I was absent about two or three weeks before, because I had to undergo many more tests so that everything would go well and... they called me, they wrote me, didn't they? And then they went to visit me at the clinic too. I also have a picture of... they were all wearing masks, because I was very weak, so they had to be super protected so as not to infect me with anything, right?

INTERVIEWER: [nods].

MAYUMI: Yes, very, very nice. And they accompanied me through the whole process.

INTERVIEWER: [nods] And talking about everything already...like...your whole time in school, taking into account both schools, uh...would you say there are things where you feel like you wanted to do more and you couldn't? You wanted to do things and you didn't feel like you were given the opportunity to do them?

MAYUMI: In elementary school [laughs].

INTERVIEWER: Especially in elementary school.

MAYUMI: Yes.

INTERVIEWER: From high school it's not something you associate it with?

MAYUMI: Uh... no, not really. No. Because there was a lot of openness for me to propose what I wanted to do as well.

INTERVIEWER: In high school.

MAYUMI: Or to say how far I could.

INTERVIEWER: Ah... they would give you... they would tell you....

MAYUMI: Yes, because even at the nikkei school level, there was, I don't know, a doka, matsuri, right? So they always wanted like, even though I don't participate, let's say, in the...in the Olympics...like it's like an Olympics, right, in a doka, like a parade, for example. In the matsuri too. I mean, yes, always like asking me "would you like to", right? And I said "yes, of course". So, like... to see the way, right? Or also... this is another part that escapes from the courses, let's say, this... physical, in quotation marks, but... in the case of field work, for example.

INTERVIEWER: How did you go about matsuri and field work?

MAYUMI: I mean, I went to the matsuri with my feet. But, for example, in the field work we went to a huaca... we went to places like that... a hill that we had to climb. So, for that, I had a wheelchair. Just for those cases.

INTERVIEWER: Who... who got it for you?

MAYUMI: My mother bought it for me. Yes, she bought me a chair and I used it to go, for example, to the center of Lima, when we went shopping, right, like... things like that... commuting, where you have to walk a long distance and for field work? So... because they were history courses, ecology courses, that is, they were academically important courses and you had to participate. So my friends took me there, they carried me, with... teachers... between four people they carried me to a huaca, didn't they?

INTERVIEWER: I mean, there was nothing you couldn't participate in.

MAYUMI: We always saw the shape. Yes.

INTERVIEWER: And that was something... that was not born from one but from all or... how did the synergy of proposing things work?

MAYUMI: I mean, it was like... the whole room has to go, right?

INTERVIEWER: [nods].

MAYUMI: It's not like you didn't go. The only place that I didn't go, and that I decided not to go, was for example my promotion trip, which was to Machu Picchu.

INTERVIEWER: And why was that?

MAYUMI: Because I felt it was very risky.

INTERVIEWER: I mean, you had the....

MAYUMI: It's that... to climb Machu Picchu... I mean, to begin with, the altitude... So, the kids... if you push me... they are kids of fifteen, sixteen years old then. They don't have the same physical condition they could have had in Lima, right, because there were more teachers there; here there was only one teacher, who was an old man who went with them, right? So, yes, there were many things that made me take a step aside and I did not go on my promotion trip. But, afterwards, I always went to all the other school activities. The field trips, for example, I didn't go either, now that I realize. I mean, the academic stuff. But the outings, it was like spending the whole day at the beach, at the swimming pool... I used to say... "not that", but because I didn't like it, didn't I?

INTERVIEWER: You didn't like it.

MAYUMI: Yes, because... There, for example, they were going to play volleyball, they were going to play those and I didn't... I was going to feel like I was going to be like when I was in elementary school and I couldn't go out for recess... Something like that.

INTERVIEWER: [nods] Did you think it was going to work differently than how things worked when it was academic, that others were going to do their best...?

MAYUMI: Yes, yes. So yes, I... no school field trip I've gone, neither elementary nor high school. For example, here in [not understood] is my first field trip [laughs].

INTERVIEWER: [laughs] Ah, how difficult.

MAYUMI: They always told me "but let's go", didn't they, my friends... and I said "no, I prefer not to go".

INTERVIEWER: What about the teachers?

MAYUMI: They also told me "let's go" and I said "no, I prefer not to go". For that I didn't feel comfortable.

INTERVIEWER: And no one ever tried to find out why you didn't want to?

MAYUMI: No.

INTERVIEWER: Your parents?

MAYUMI: No. It's even better for them, right, because... because they said, like, no, I mean, I think it's like "be careful, you'll fall, be careful, something will happen to you", right?

INTERVIEWER: [nods] And there... How was this... what we talked about at the beginning, well, not at the beginning... some years ago, in your elementary school days...?

MAYUMI: [nods].

INTERVIEWER: Do you remember being referred to as 'enfermita' [“enfermita” means an “ill person” but making it sound less impersonal]? That word...

MAYUMI: Not like 'sick', but she's kind of sick.

INTERVIEWER: Ah... malita [“malita” is referred to address a person that has an illness, but the disease is not that important as its condition is something the others are familiar with].

MAYUMI: Yes, isn't it? **MAYUMI:** Yes, yes.

INTERVIEWER: Malita, sorry. The word 'malita' - did that happen again in high school or something like that?

MAYUMI: Uh... no. No. But I something I found out much later, just a couple of years ago, that I talked to a friend who is a promotion older than me, so she's not from my class, and she told me that the principal went through every class to talk about me.

INTERVIEWER: [nods].

MAYUMI: And she went to each classroom to tell them, "This girl came, she's in the first year of junior high school. Please support her in whatever she needs," right, "I don't know what...", so... I mean, now that I think about it, I'm like "wow... what...". I think it's a nice gesture, isn't it, because they are children... they are kids who don't have that... I mean, as if to warn them and also to make them feel responsible that they had to make me feel welcome.

INTERVIEWER: Because it's not such an easy thing for you to feel....

MAYUMI: I mean, maybe if she didn't say it, something similar to what happened in elementary school would happen, all of a sudden, I don't know... I don't think so, because they were much calmer kids, right? But she always did... the warning.

INTERVIEWER: And at this stage of your life, the word 'disability' didn't ring a bell at any time.

MAYUMI: No, not at all, not at all...

INTERVIEWER: How did they refer to your situation? Or if they ever referred to?

MAYUMI: Like newly operated, right? Or like "she's got a bad hip", something like that?

INTERVIEWER: [nods].

MAYUMI: But, as I tell you, this duality of "my body is one thing and I am the other," so... it's not that I have a disability; it's not that I'm the one that's wrong, right?

INTERVIEWER: How is that, could you explain it again?

MAYUMI: I mean, I always... since I had this duality that one thing is my body, another thing is me, I didn't represent myself as a person with a disability either, right, but it was like "oh, I have a bad hip", you know, it's not that I have a bad hip: it's my hip that's bad, right?

INTERVIEWER: And were there other people that you identified as people with disabilities?

MAYUMI: No, neither in elementary nor in junior high school.

INTERVIEWER: And outside of school, in your life?

MAYUMI: Neither.

INTERVIEWER: Not even when you were doing your rehab... when you had your surgery either?

MAYUMI: Uh... But I didn't identify like "this is a person with a disability", but like "ah, look, this person has a bad arm, this person has a bad..." [laughs].

INTERVIEWER: You have one part wrong?

MAYUMI: That part.

INTERVIEWER: That part. There's one part that's not right.

MAYUMI: Yes, yes, because also, let's say, the therapists saw it that way. That's also how they named people, right: the foot, the hip, the spine, right?

INTERVIEWER: And that was more or less how they referred to your situation in high school: "it's bad from that part".

MAYUMI: Yes, yes.

INTERVIEWER: And did that give you any feeling of... like "ugh... ugh... to be referred to in that way"?

MAYUMI: Because I said so.

INTERVIEWER: Ah...

MAYUMI: Yes.

INTERVIEWER: Oh, you were saying?

MAYUMI: Yes.

INTERVIEWER: Were you the one who said "I have a bad hip"?

MAYUMI: Sure, then I repeated it more....

INTERVIEWER: If you didn't say, then no.....

MAYUMI: I don't know... [laughs].

INTERVIEWER: Oh no... It never happened that you stayed...?

MAYUMI: No, no, no, no, no. Yes.

INTERVIEWER: Uh... I asked you another question about... at the beginning, right, if you feel that... there is something... if your experience in school was satisfactory and you said "we have to make a division between elementary and high school".

MAYUMI: [nods].

INTERVIEWER: Now I ask you that question for high school: do you feel that your experience going to high school was a satisfying experience?

MAYUMI: Yes, yes.

INTERVIEWER: What made it, if you could pick something or you could explain it...what made it satisfying?

MAYUMI: The atmosphere there. Yes. It was very, very nice. It was...like a second family, I think.

INTERVIEWER: Did you ever feel different from your peers?

MAYUMI: It's just that in school I think the difference wasn't so much about...someone's running ability or something, but more about ethnicity.

INTERVIEWER: [nods].

MAYUMI: So maybe, if I felt different, it was because I didn't feel Nikkei enough, because I was uh...my dad is not Nikkei.

INTERVIEWER: Oh yeah.

MAYUMI: That's why. I mean, that was like more of a theme that I was more aware of than the other thing. Yes.

INTERVIEWER: Because your mother was Nikkei.

MAYUMI: [nods] But there were boys, girls, who had both Nikkei parents.

INTERVIEWER: [nods].

MAYUMI: And on top of that they had lived in Japan and they spoke Japanese. So it was like this... this list of... "oh, by comparison, so I'm not Nikkei enough," right?

INTERVIEWER: [nods] I understand. I think it's happened to me [laughs]. Uh... When is it that... - I know this comes out of school - but when is it that the word 'disability' takes on a meaning in your life? Has it ever made sense in your life? More I wonder that: has it ever made sense in your life?

MAYUMI: Uh... Back when I was in college, I remember there was a newspaper, at the university, right, that we had. And there was an article written by a guy who unfortunately passed away, his name was... Rispa, his last name was, Kikín Rispa, Enrique Rispa. He was a professor of management. And he was a professor who had cancer and had to have his leg amputated. So, in this article, he was talking about functional diversity as a concept that there are bodies that function differently. So I said, "I think that's me," right? That is, to understand that my process to move, to walk, to do certain things is different from that of the hegemonic body, right? So... but I saw that in 2013 and it was much later when I started to say "ah...", that I have functional diversity, right? And there are people who... from the disability community who say that it is rather a euphemism and that we should say 'disability' and take ownership of the word. Eh... But for many people I felt that I was assuming an identity that did not correspond to me by calling myself 'person with disability', because in the Conadis exam or... like the difficulties faced by people with disability I did not have them.

INTERVIEWER: Did you go through an examination of... identification...?

MAYUMI: No, no, no. But, when I saw on the internet, I didn't... I couldn't... I mean, no, I didn't qualify as a person with a disability.

INTERVIEWER: Your parents didn't... never put you through that?

MAYUMI: No, no, no, no, no.

INTERVIEWER: So when they sought uh... these concessions that you say in primary and secondary school....

MAYUMI: It's just that, as I said, it was only this knee that flexes. I mean, it is almost always assumed as 'disability' when it is something a little bit... like a diagnosis, for example. How many times have I been asked "what is your diagnosis" and I don't have a diagnosis. I mean, I don't have like polio, like... this... I don't know... blindness... like that kind of thing that exists... pre-existing diseases that mark you... that mark you as having a disability. I don't have that.

INTERVIEWER: [nods].

MAYUMI: So that's why I felt like I didn't belong...it was kind of strange that I used a term that didn't really fit me.

INTERVIEWER: That already... in your college days....

MAYUMI: Yes. So I preferred to say like "I have physical limitations or I am a person with functional diversity", right?

INTERVIEWER: And that word 'physical limitations' also acquired...popped into your head when you started going to college, not before.

MAYUMI: Yes. No, no, not before. Yes. I mean, this "he has a bad leg"... it's better "he has a limitation", isn't it?

INTERVIEWER: [nods].

MAYUMI: Or a person with reduced mobility as well, for example, right?

INTERVIEWER: [nods].

MAYUMI: Because I also started doing disability research in college. So learning more about the social model, right, as opposed to the medical model?

INTERVIEWER: [nods] And after you have finished school, have you kept track of... have you kept track of whether other children who have had any limitations of any kind have come to your primary or secondary school?

MAYUMI: No. Not really. In high school, at least from what I see on social media, it seems not.

INTERVIEWER: [nods].

MAYUMI: Also, the school moved again. And then...I mean, now they've moved again...now they've moved to a building with many floors. So I don't know how accessible it is.

INTERVIEWER: [nods] Were there things that at home you could do that at school you couldn't do, or did that never happen?

MAYUMI: No, no, no.

INTERVIEWER: Rather there were more things you could do at school than at home?

MAYUMI: No, it's the same. Yes. I've never felt limited at home or in high school.

INTERVIEWER: Oh, we are talking about high school.

MAYUMI: [nods] Yes. I was very young in elementary school too, wasn't I? Yes.

INTERVIEWER: And did you do any kind of extra curricular activities that you didn't mention before? You mentioned matsuri; you mentioned?

MAYUMI: Ah, but it wasn't as an activity... I mean... you mean... as a sport that I did on my own, something like that or how...?

INTERVIEWER: No. I mean things that involve getting out of school, things that involve doing things in the street, visiting places... getting around....

MAYUMI: ...as part of the school program or...?

INTERVIEWER: No, as part of being a child... or being a teenager.

MAYUMI: I mean, going out with my friends, that...?

INTERVIEWER: [nods].

MAYUMI: Yes, yes, yes, yes, yes. Not as much as I would have liked, because there was always this issue of... "I have to take a cab". I didn't... by that time... I only started to take a bus in college, after my third operation. Before, I didn't take a bus. So it was very difficult to go places, because it was by cab, wasn't it? So that did limit me from going out sometimes.

INTERVIEWER: [nods] If there could be any... if you could take a trip back in time and say something to the adults of the past so that they would do something better that would have made you....

MAYUMI: By education you mean... the teachers, the...?

INTERVIEWER: Where and when would you have chosen to travel and what would you have done?

MAYUMI: Eh... I think that, to begin with, it would be like going to San Juan de Dios, because there the medical model, at least when I studied, was very marked... when I was there, wasn't it? So, that model of "you have to heal yourself", like "you have to be normal; we are going to do this so that... how to focus...", like I tell you, "the leg patient, the knee patient, the arm patient...". So it is like... to make this person well or rather that his arm, that his leg is well, but they forget that this arm, this leg is inside a whole person, that it is not only a body, but also thinks, feels, listens, right? So, there I feel that there is a lot of work to be done, I don't know if it has changed lately, but... that chip of making you feel that you have to be well and that until you are not well you are not complete, I think that would be what I would point out to them so that they do not keep repeating that.

INTERVIEWER: Do you consider St. John of God as a sort of extension of the school or a totally different thing?

MAYUMI: No, no, totally different. Yes.

INTERVIEWER: [nods] I mean, you were separating a place that was....

MAYUMI: It's just that I was younger too. Yes, and they were not like classes, right? I used to go and I had... eh... There was a part like psychomotor skills, like reasoning, things like that, which helped me a lot when I was little, as stimulation... And from there, swimming pool, hydrotherapy and from there, mat therapy, those things... Nothing more.

INTERVIEWER: [nods] But all of that was accompanied by messages of "you have to heal yourself; you have to...".

MAYUMI: From the therapists and the doctor too. I mean, my childhood is very much marked by the doctors... like the doctor on TV, making me walk. And since this place was also big, uh... they took students... medical students. So, imagine a five year old girl, making her walk with her pants off... with thirty medical students watching her and taking notes, and the doctor/professor saying "let's see, what do you think she has? And what do you think...", right? I mean, like an object, right?

INTERVIEWER: [nods] I'm very sorry that you have....

MAYUMI: No [laughs].

INTERVIEWER: Well, I hope you were entertained, that you found something productive... something that you were able to take away for yourself... because I definitely think that I can take away a lot of things from here for my research.

MAYUMI: Ah... that's good.

INTERVIEWER: So thank you very much.

Interview N°2

INTERVIEWER: So, well Andrea, thank you. I also wanted to ask you that if there is any question that is uncomfortable for you, please let me know. And if during the interview there is personal information that you realize, that you would not like me to share in a transcript, at the end of the interview we can do a review of what we talked about and you tell me, okay? Then, to do it formally you could give me your name or what you would like me to call you during the interview.

HIKARI: My name is Andrea Burga, it's okay to call me Andrea.

INTERVIEWER: Ok, Andrea, would you like to make a brief introduction about yourself? I mean, for example, your age, what you tell yourself, who you are, what you studied.

HIKARI: Ok, my name is Andrea Burga, I live in Lima, Peru, I am 29 years old, I am a journalist, I currently work in an NGO that sees disability issues, I work in the area of communications. I am a creator of content on disability issues in social networks, on Instagram and TikTok, especially. And well, I have also participated in artistic projects because I'm actually a singer and that.

INTERVIEWER: I don't know you personally, but it seems to me that I've followed you, I'm not sure I've followed you on Twitter and I knew a little bit that you were also interested in everything that had to do with art and it seems to me something quite interesting that you were so, let's say that you were talented in so many aspects, that normally a person is not dedicated to do so many things, but I was impressed. But that in part I was very interested to be from this interview. And by the way, there's something I didn't mention, but I'd like to know, have you had any preparation or have you studied anything to do what you do? Of the many things that you do.

HIKARI: Well, I studied journalism, you mean that? I studied at the Catholic University.

INTERVIEWER: Yes, also, but as you mention, to dedicate yourself to several things, I was asking if you have received any preparation, besides, for singing, for, I don't know, acting, maybe.

HIKARI: I have taken singing and dance lessons, but independently, that is, with teachers, not in a particular institute.

Okay. So, you studied journalism at the Catholic University.

HIKARI: Yes.

INTERVIEWER: And oh yes, how many years ago was it that you finished?

HIKARI: I finished in 2019-2018, around there.

INTERVIEWER: Ah, ok.

HIKARI: I didn't remember well, because what happened is that I finished, that is, in one year and the following year I graduated, I think. That's why my memory is a little fuzzy.

INTERVIEWER: No, of course, I understand. It is a timing issue that, when you finish in one period you have to wait until the next one.

HIKARI: Yes.

INTERVIEWER: Ok. What is your routine in your day to day life? What is your routine normally like?

HIKARI: Well, now I telework. So, the usual thing is that I get up for breakfast and I start teleworking, then some days, some days, for example, I am doing functional training, let's say before breakfast, some days I train. as I said work, generally to make videos for social networks I do them in the afternoons, or sometimes what I do is organize myself and a whole morning I make videos because, let's say, the schedule I have at the moment is quite flexible and I can organize myself a little bit. I mean, if I organize myself I manage to have a free morning and make some videos and then save them for publication. And well, when I take singing classes, or dance singing classes, which I haven't been taking lately, but when I take them they are usually in the afternoon.

INTERVIEWER: Do you organize yourself doing all this also in a, what do you call it, remote way or do you do it in a place with a group of people?

HIKARI: Dance... In the case of artistic things, dance is more face-to-face. Well, I have a friend who comes to my house who is my teacher, who teaches me. Well, I have not been in dance for several months now because, well, I have had some economic complications and I could not pay for the classes... because it is a matter of, no, as I have to pay for private classes it is more expensive. So... but of course, usually in dance they come to my house, and in singing it is at a distance.

INTERVIEWER: Where do you do... So, most of your stuff you perform from home, is that right?

HIKARI: Yes, yes, right now yes.

INTERVIEWER: And before, was there a before when you went out more to do things?

HIKARI: Yes, before pandemic, before pandemic I went out more. Before pandemic, for example, I remember that I had subscribed to a gym. From there, before pandemic I worked for a while in person, I worked at the Catholic in fact. And I also took English in a face-to-face way, that is to say, I took several things in a face-to-face way. Now, for example, when I have taken English I have also taken it virtually.

INTERVIEWER: And has it become more favorable to you or does it have its pros and cons like anything else?

HIKARI: No, I do prefer virtuality because I avoid transportation.

INTERVIEWER: Okay, I understand, do you currently live with someone or do you live on your own?

HIKARI: Yes, I live with my mom and my dogs.

INTERVIEWER: And have you lived like that for a long time or since when do you live with your mom and your doggies?

HIKARI: It's been a while. Before we had a lady who came to my house to work, now we also have a person but she comes some days. Because the lady used to come from Monday to Saturday, so it was like living with her a little bit. But, let's say that the lady no longer worked with us since last year, so since last year we are more alone with mom.

INTERVIEWER: So most of your life has been lived with your mom?

HIKARI: Yes, because my brother went to the United States about 7 years ago.

INTERVIEWER: Ok, so also a good part of your life let's say at home was your mom and brother.

HIKARI: Yes.

INTERVIEWER: And have you always lived in the same house, or have you ever moved?

HIKARI: Yes I have moved, but about 10 years ago to where I live.

INTERVIEWER: Where did you do your schooling, early childhood education?

HIKARI: I studied, look, the kindergarten I said in a regular elementary school. From first to third grade I was in a special basic school, but the policy of this special basic school was that students should go to regular schools. So from the fourth year of elementary school onwards I was in regular elementary schools until the fifth year of high school.

INTERVIEWER: Up to fifth grade?

HIKARI: Yes, until fifth grade I was in different schools, but in regular elementary school.

INTERVIEWER: Oh, okay. So, have you been to, like how many schools?

HIKARI: Oh, a lot, let's see. I mean, since fourth grade or in general in my whole life?

INTERVIEWER: In general in your whole life, you have changed several times.

HIKARI: Yes, let's see, one, two, three, four, five, more than seven, more than six.

INTERVIEWER: And most of the changes have occurred in primary or secondary school?

HIKARI: In elementary school.

INTERVIEWER: And your preschool, did you always do it in the same place?

HIKARI: In regular elementary school. Yes, I only did fifth grade... fifth, what am I talking about. Five years of, of my... I don't know if at that time it was.... I don't know what the nest is like because I didn't do three years, no, now all the children go to three years, I only did five years. So I don't know what that must have been like.

INTERVIEWER: I don't think it was compulsory to do all three before. Then it was optional, it depended on the family.

HIKARI: Yes, now I guess it's mandatory, because all the children I see are going to three years.

INTERVIEWER: Yes, I think it is mandatory now. So the preschool, let's say, the five years, did you do it in the same school where you did the first year of elementary school?

HIKARI: No, no, I did kindergarten in a regular elementary school.

INTERVIEWER: And the first to third in a basic special.

HIKARI: Exactly.

INTERVIEWER: And how was that policy where at the end of the third grade you were asked to.... Kind of like they assigned you to a new school, they referred you to a new school, how was that?

HIKARI: No, they didn't refer me, I mean, my parents... mom had to look, but they had this thing that, let's say, you kind of graduated.... It's not that you had a ceremony of anything, but let's say that between meals you had to leave school. In other words, the school would tell you that, well, we taught you everything here and you had to look for a regular elementary school. And that's how it was.

INTERVIEWER: And what was... well, I know you were very small, but what was supposed to have been that essential that from first to third you were graduating from that training or that preparation, what was so particular about it?

HIKARI: I mean, my school was like a school, let's say, of.... I mean, like... I mean, they taught you to read, to write, to add, to subtract, to multiply. I mean, but obviously they taught you with an adapted methodology. I mean, for example, blind children were taught Braille. At that time I had low vision, that is, because my condition has caused my vision to progressively decrease. So, when I was six years old, I could see a little. So they wrote very large letters, like.... Arial 30, that is, very big, very big. I wrote and then they gave me adapted material so I could learn to write. That's what they do with many children, they give them didactic material, but obviously what they did was to give me material with more contrast. For example, the notebooks I used were notebooks with thick lines, that is, with bold and well marked lines so that I could see them. In other words, the teaching was with adapted material, but in third grade, that is, in the last year, let's say, that you finish in that school, what they taught you, that is, we had, I think it was from eight to one in the afternoon, common classes, common math or communication or whatever, and at two in the afternoon, I think, we had some afternoon classes in which they taught us daily life activities. They taught us, for example, how to place ourselves in space, they taught us how to make the bed, they taught us how to... for example, a flan salad. for example, a fruit salad. In other words, they taught us various little things about daily life. They taught us a little bit to introduce us to... a little bit to spaces in a more independent way, to other spaces in a more independent way.

INTERVIEWER: Was it like housework, something like that?

HIKARI: How?

INTERVIEWER: Was it something like, they were dedicated to instructing you in household chores, something like that?

HIKARI: I mean, I think that more than household chores they are daily activities, because, for example, we had a course on orientation and mobility in which, of course, blind people were taught to use the cane, but they not only taught you how to use the cane, but they also taught you, for example, what a traffic light was. And they would take you, like, to an avenue. Obviously all of this was with adult supervision, no. And they showed you how the traffic light worked, no. And they showed you what a block consisted of, that is, things like location, or how it was, how a park was, how a park could be laid out, all those location things they taught you. And apart from those activities of daily life, like having your bed, making a fruit salad... there were several activities that... oh, folding clothes, tidying things up, that is, like those kinds of activities of daily life.

INTERVIEWER: Uh-huh. And all that in the three-year range.

HIKARI: In the third grade. We were 8 years old.

INTERVIEWER: Oh, right. The school you attended, was it a private school or a state school?

HIKARI: It was state-run, but it seems to me that the figure of the parishioner was a bit of a figure because there were nuns who went.

INTERVIEWER: But it was not a "Fe y Alegría".

HIKARI: No, no, no, no, this school was in fact supported by the Franciscan order, I think.

INTERVIEWER: Ah, so it could have been parochial. It could, it could have been parochial.

HIKARI: Yes, in fact it still exists but it is no longer focused, it's just that this school was specifically focused on visual abilities, but now it is focused on other disabilities. It is still a CEBE but it focuses on other abilities as well.

INTERVIEWER: And how did your parents, or your mom, sorry, find this school for you?

HIKARI: Oh, an ophthalmologist recommended it to my mother, she went there, took me there and recommended that school.

INTERVIEWER: Any restrictions, do you remember, that they had, well, that you heard about that they had in order to enroll you or...?

HIKARI: In the CEBE, in the school of the Básica Especial?

INTERVIEWER: Yes.

HIKARI: Not that my mom told me.

INTERVIEWER: I mean, there were no conditions or any commitments that they asked your mother to make for you.

HIKARI: No, I think it wasn't commitment, but I think my mom always knew that I wasn't going to stay there, that eventually I was going to get out.

INTERVIEWER: Okay, so, it was kind of a temporary measure from the beginning.

HIKARI: Sure, I mean, it was a school where, yes, I was going to be there for a few years.

INTERVIEWER: Ah, okay, I understand. Okay, your routine when you were attending, when you started attending school, what was your routine like back then, when you still say you had low vision, but you got to manage through your eyes, more than anything else?

HIKARI: I mean, yes, but well, my parents accompanied me, because apart from the child, right?

INTERVIEWER: I mean, at home, when you get ready for school, is your mom the one who was with you helping you or did you do things for your.... What was it like? I want to imagine, more or less, what your routine was like, when you were getting ready to go to school, when you were coming back.

HIKARI: I remember that yes, I used to put on my uniform and of course, my mother would comb my hair, and my parents would take me to a point where a car would pick me up, because that school was very close to me, it was in surco and I lived in Callao. So my parents would drop me off at a point where a car would pick me up. I don't remember if they paid for this transportation, but it was a transportation from the same school that picked up the children.

And, sorry, those are my dogs. And, well, the mobility took me to school, that is, I went alone with the other children. And when the car would pick me up, it would also take me to a point where my parents would pick me up. And in the afternoon they helped me to do my homework, which I think they left me in their.... I don't remember very well.

INTERVIEWER: No, it's okay.

HIKARI: My parents helped me or maybe the lady who worked at my house, I think she joined me at some point and also helped me.

INTERVIEWER: And regarding when you were in the nest, do you remember more or less things from the nest or are they fuzzy memories to be able to talk about that?

HIKARI: No, I mean, I only remember that I did some things, like going to a chocolatada or making necklaces with little sticks, with little pieces of sticks. I mean, I remember the didactic things we did.

INTERVIEWER: But impressions of what that nesting experience was like, let's say they are part of your memories, how you followed you, if you felt welcomed, those things, for example.

HIKARI: No, I don't remember, actually.

INTERVIEWER: Ok. And in school from first through third grade, do you have memories about those feelings?

HIKARI: I remember playing a lot with, well, that's where I met one of my best friends, so this.... Yes, well no, I remember playing a lot with all the children and.... I remember that in those years I learned to do the... the basic exercises, right? Like adding, standing, multiplying and dividing. Yes, in this school I remember many things, especially because, as I was saying, we worked with adapted material, so I remember that we had a giant blackboard, but a giant one, because there I wrote, we wrote in big letters. I mean, I remember several things like that, right? Of several exercises I did, of playing with the children.

INTERVIEWER: So it was a school where you had a lot of friends? So I was asking you, so you in top or bottom schools, you made quite a few friends, did you feel pretty much like you... you made a lot of friendships, you didn't have a sense of loneliness or anything like that?

HIKARI: No, I mean I did have several friends.

INTERVIEWER: And do you remember how adults behaved back then? If you ever felt anything like discomfort, anything you didn't like.

HIKARI: How did the adults behave? Yes, in fact, I mean, I remember my teachers from those years very much. There were two of them, especially. Yes, the treatment was nice, I mean, from them.

INTERVIEWER: What was it that made it beautiful?

HIKARI: Because they were very close to you, that is, they cared a lot about you, and they were very present in the learning process. Besides, they were the teachers who taught me the basics, right? They taught me how to write, how to read. So, of course, I feel that they are very important, that one remembers them very much for that reason, right?

INTERVIEWER: And when you say they were very close, how did they express that closeness? Do you mean that... Excuse me, excuse me, one second.... I was asking yes, that closeness that the teachers had with you, was because you felt that there was enough physical contact, they talked to you enough, you felt that they had a special sweetness, like, I don't know if you remember those details.

HIKARI: Yes, I mean... Of course, I mean, they were kind of affectionate, because we were children, I mean, they were demanding, but for example when.... I don't know, when they had to play games, they played games. And so on.

INTERVIEWER: I'm sorry, I was a little bit confused when they knocked on my door. Let's see, then, at that stage of the school, do you remember if the teachers had any special way of referring to the students, if they had any kind of particular speech about you?

HIKARI: In this school at CEBE?

INTERVIEWER: Yes. For example, relative to who you were, something that defined who you were as part of your identity. I was talking for example, at CEBE, mes you say it specialized in serving people with blindness or low vision, right?

HIKARI: Exactly, zero or low vision, yes.

INTERVIEWER: And did they make references about it when they were talking to you, about things to value or how they should be valued or something like that?

HIKARI: No but, now that you ask me like this, I think what happened at school was that, for example, people with low vision shouldn't learn Braille, for the teachers, because they said that it would mean that they wouldn't be able to... I mean they would get used to Braille and wouldn't want to use their sight or something like that, no, so it was like, something like very, you have to learn to read with your sight, you can't learn Braille. And they didn't teach us how to use the cane either, they didn't teach me how to use the cane. I think that happened a little bit, no, like it was very low vision on one side and blindness on the other. Not on the part of the children, because we children play with everyone, but on the part of the teacher, I don't think.

INTERVIEWER: And they were in separate classrooms?

HIKARI: No.

INTERVIEWER: So what varied was that within a classroom they could receive something like differentiated instruction. Some were taught with braille and others were taught as adapted materials, something like that?

HIKARI: Yes, yes, it seems to me that, for daily life activities, sometimes they did some kind of division, but I don't remember that well. I think they did separate us a little bit, I think but I don't remember well, I don't remember that well but, but of course, I mean, for example, when, in math class a child could be with his Braille machine and on the side and I would be writing, no, with my notebook.

INTERVIEWER: And when they made this differentiation, how did they mean such, such must do this, or such can do this, and such cannot do this and vice versa? Something like "those people, or you who can see, or you who can't see," something like that, was there that kind of language?

HIKARI: No, there was a very strong language of, I mean, they taught us this, no, that the language is low vision and blindness. It's not like you can't see, no, no, no, it was, I mean yes, they use the proper terminology.

INTERVIEWER: What is the terminology you remember?

HIKARI: Low vision and blindness. You are a person with blindness, you are a person with low vision .

INTERVIEWER: Any other terminology that you also remember quite a bit?

HIKARI: No, more that one, in fact at that time I don't remember so much the term disability.

INTERVIEWER: And adapted materials was also part of the terminology?

HIKARI: No, no, because I didn't know how other children worked, so for me that was normal.

INTERVIEWER: Ah, ok, of that there was none, there was none, nothing that would draw attention to what they were doing, that would make them think they were different.

HIKARI: No. I mean, yes, I mean maybe I noticed that because I have a brother, but he is a much older brother. So of course, sometimes, for example, I noticed that he had a different notebook, but well, I assumed it was because he was older, maybe not, because it didn't seem strange to me.

INTERVIEWER: Well, yes, you were quite small then. And about how to take care of themselves, was there any, in the language, any particular allusion to how they should take care of themselves?

HIKARI: I don't remember.

INTERVIEWER: No problem, just in case you remembered. So, already, I think I've asked you quite a few questions from that period. So you say that in third grade there was sort of a graduation and they had to find you a new school.

HIKARI: I mean, it wasn't a ceremony, nothing, I just came out of there, right?

INTERVIEWER: And that new school, was it also far away from your home?

HIKARI: No, no, it was a school that was closer.

INTERVIEWER: And how long were you in that school?

HIKARI: One year.

INTERVIEWER: One year, and why did you change schools? Why was there a change of year?

HIKARI: Because what happened is that in this school they did not want to put me in the classroom I was supposed to be in. I was supposed to be in fourth grade and they wanted to put me in a different classroom because the teacher who was supposed to teach me taught second or third grade, I don't remember exactly what it was. In other words, there were several problems there that I don't remember well. But the thing is that they didn't want me to be in my classroom. Or sometimes what they did, I think, was to take the classroom away from me and my classmate because I was in that school with a classmate.

INTERVIEWER: Ah.

HIKARI: And they made us feel like we were in other spaces, like we were alone.

INTERVIEWER: For what purpose was that space?

HIKARI: I mean, because as I said, the teacher who was supposed to teach us, I mean, she could kind of explain things to us, well, let's say that she did not teach in that classroom, in the fourth grade, she taught in another classroom. So that's why they put us in another classroom.

INTERVIEWER: Was it about methodology for the use of the materials?

HIKARI: Of course, their justification was that no, I mean, we could not learn at the pace of the other students.

INTERVIEWER: Just like what they said, is that how you remember them?

HIKARI: I don't remember it well, I mean, I don't remember the words, but I remember the context.

INTERVIEWER: Sure, there, it made you, for you, let's say, it makes sense to you that that's what happened.

HIKARI: Yes.

INTERVIEWER: In this school, what was the relationship with your classmates like?

HIKARI: I remember it was good. I don't remember the children so much, but I don't remember it being bad either. I mean, I do remember playing with them sometimes.

INTERVIEWER: So you could say that what I remember most were these abrupt changes.

INTERVIEWER: ...This singing. So as not to waste more time and not to steal more time than I can give you. I was asking you, then, from this stage of fourth grade, maybe what you, what makes you, what reminds you the most is this abrupt change in which you were taken out of the classroom and moved to another one.

HIKARI: Yes, yes, I mean, I remember that of course, as I was saying, I got along well with the children, but I do remember that situation of exclusion in the academic field, no, I don't. I mean, more let's say... pedagogical... I don't know what to call it, but let's say not being able to learn with them, right?

INTERVIEWER: And did your colleagues make mention of that? Because I imagine they were aware of what was going on, weren't they?

HIKARI: I don't know because we were 9, 9, 10 years old.

INTERVIEWER: Did they ask them why, where they were taking her, why they had to change grandmothers, or did they just assume it was something that had to happen?

HIKARI: I don't remember, I guess they may have asked at some point, but I don't remember.

INTERVIEWER: Okay, and so, those decisions that the school was making you feel more uncomfortable. Your mom wasn't satisfied with that either.

HIKARI: Yes, my mother was not satisfied and that's why she changed me to another school. Of course, I wasn't satisfied either, I guess, because... because I remember I was very attached to my classmate. And I do remember that when she was absent I felt kind of sad. So, I couldn't tell you, I couldn't answer you, like, this made me feel that way. But I could tell you that things like this happened. That for example if my partner was absent and it made me sad. So I guess if that happened it was because something wasn't right.

INTERVIEWER: Sure. And, in fifth grade you were moved to a school that was also relatively close?

HIKARI: Yes, in fifth grade they moved me to a school nearby. But I think I was there for only two or three months. The school is in San Martín de Porres. At that time I lived in El Callado but it was on the border with San Martin. And I think I was there for a few months and I don't even remember why they took me out. I think it was also because the teacher didn't want to teach me, or something like that.

INTERVIEWER: What period do you have a better memory of? Not better in the sense that you liked them better but that you remember in better detail the things that happened.

HIKARI: Let's see, I'll tell you chronologically and then you can ask me again. I was in this school for about four months, a few months more. And then they changed me to a small school, also near my house. But I could walk to this one, because the previous ones I told you I couldn't, I mean, they were close but I couldn't walk there. And that school was literally a very small school. One of these super informal private schools and I think there were five of us students in the fifth grade classroom and I remember, I mean, with the teacher it was very easy because there were only a few of us. So the teacher helped me, I mean, she taught me well, she played with the children, in fact, one of the classmates I know until now, right? I have her on social networks until now. So I did very well there, the thing is that the school had no more classrooms, no more grades, so in sixth grade I moved to another school. I also stayed there for a year because there were also problems with the math teacher. It was a school that had more students, about 36 students per classroom I think, and of course, I played with the children from time to time, but not always because I remember that in that school, for example, I remember being alone during recess many times, in sixth grade. There was a communications teacher there, for example, who did teach me, that is, she was dedicated to teaching me, but not the math teacher. I have been in many schools, because educational inclusion is horrible, but at that time I think it was worse. In the first year of high school I was also in a school and I also left because I also had some problems with some teachers, so... but since I was already a teenager, well, I did interact with some friends, not so much with games, no, but more with, I don't know, like watching a movie or something like that. So I did have some interaction with the kids. In fact, I also have some friends from there. But also the same thing, no, I had problems with the teachers and, for example, in the first year of high school I started to use a laptop to take it to school and take notes, I no longer used only the notebook, and there I was also losing my vision.

INTERVIEWER: Was that on your mother's initiative or was it a recommendation?

HIKARI: Sure, at that time I was on the borderline between sixth and first grade and they put me in some courses to learn how to use the computer with the screen reader. I don't know how my mom found out about the course, I don't think she remembers anymore either, but the thing is that she found out about a course and got me in, and there they taught me how to use the computer.

INTERVIEWER: To handle technologies, that is, to use this program to increase the size and readability of things?

HIKARI: No, it was not to increase the size. I think I once took a course to increase the size but this was a course to use the screen reader, this is this software that reads everything that is on the screen. And then in the first year of high school I started to take a laptop and that's where I took notes. And by the second year of high school I stayed in only one school, which was a few blocks from my house, and I stayed because, as I said, it was already very tiring to look for schools because, as you can see, I went to a lot of them. I had problems but I was trying to handle them with a private teacher. I had some friends so I stayed there until fifth grade.

INTERVIEWER: What kind of problems were those that justified or warranted a private tutor?

HIKARI: It was for the mathematics, physics and chemistry courses. They were the most problematic courses.

INTERVIEWER: The science ones?

HIKARI: Yes.

INTERVIEWER: Oh, I understand. And when you graduated, did you get to feel like you were part of the group you were graduating with, or was that not such a big deal to you at the time?

HIKARI: I was part of a group, because I had some friends there. Not the whole class was... I mean, yes, the whole class were my friends, but let's say I had some close friends, no, so I got along really well with her. But of course, it's not that the school was a stage I would go back to, no, it's not that graduation was super motivating, no, not at all.

INTERVIEWER: From what else I have been telling you, it strikes me, suddenly I have not understood well. I would like you to help me clarify. When you were being made to change schools, was there always this sort of requirement that the homeroom teacher or homeroom teacher that you were going to be in had some sort of training or felt, or accepted that you would be integrated into their classroom? Was there a sort of condition of almiento like that?

HIKARI: How? I didn't quite understand the question.

INTERVIEWER: Was there any kind of conditioning when you changed schools that the classroom teacher, or the tutor of the classroom where you were going to be integrated, had to accept your integration into the classroom? In other words, was there a sort of "it was up to the teacher" to change schools?

HIKARI: I mean, they would change schools basically because it didn't work out. And when I went to the other school, of course, it was like, well, yes we are willing to accept you, let's see how it goes. Or sometimes they would also talk to the teachers about.... I remember one time my mom wanted to put me in a school and the teacher said no. The teacher specifically said no. The teacher said no. The teacher specifically. But there were also principals. Of course, I was in many schools but I was also rejected from many schools. I mean, my mother looked for many schools, and many of them said no to me and I was rejected directly by the teachers or directly by the directors.

INTERVIEWER: All that, it was your mom who brokered for you, right?

HIKARI: Yes.

INTERVIEWER: And all those things, did your mother tell you, or did she tell you later when you were older?

HIKARI: He told me about them at the time and he also told me things when I was older.

INTERVIEWER: And is there anything that struck you, that you found out already when you were older?

HIKARI: From school... Not that I remember.

INTERVIEWER: Suddenly it's not relevant. It's just something that had occurred to me. So, something you just said, that you said a moment ago that no, if you could not repeat that experience, the experience of being in a school, of being in all these different schools, you would save it, something like that could sum up that feeling?

HIKARI: I mean, in most of the schools I've been to, yes. In some, as I say, it went well. But most of them did not. And in high school, for example, it happened to me that there were teachers with whom I did well and others who did not.

INTERVIEWER: And what did that depend on?

HIKARI: From the teacher.

INTERVIEWER: Of your own free will?

HIKARI: Yes, of your own free will.

INTERVIEWER: When you were there, you told me that the more you progressed through the grades, there was also a greater loss of vision. So, the computer was for you the medium by which you managed the most during the classes?

HIKARI: Yes, starting in high school, yes.

INTERVIEWER: And in what way is the computer becoming your ally?

HIKARI: As I mentioned to you when I was put into this course.

INTERVIEWER: That it was to use the reader.

HIKARI: Yes, it was to use the reader on the computer.

INTERVIEWER: But back then you already all the notes you took, you... you used the keyboard to take notes during class.

HIKARI: Yes, I was taught to use the keyboard, I think when I was a child, I was taught by a teacher, I think, I remember.

INTERVIEWER: In your elementary school, in the parochial school, or in another school?

HIKARI: No, I think in a private tutor.

INTERVIEWER: Oh, I see.

HIKARI: I mean, in the parochial school I think they also taught me how to use the typewriter. But then they taught me the keyboard again, I mean the keyboard, a computer with this private teacher. I have had many private teachers throughout my life.

INTERVIEWER: I can imagine. Sorry for bringing you, luckily, having to go through so many things. I feel a little guilty. These private teachers that your mom got for you, were they referrals that she found for herself, or was it a referral teacher...?

HIKARI: Some were from the school I was in. In... from first to third grade, the CEBE. Yes, most of them were from there.

INTERVIEWER: And do you have a lot of appreciation for that teaching, being able to use the keyboard, or is it something that ties them together as part of your life, there's nothing special about it?

HIKARI: I mean, yes, I mean, yes, of course, it is valuable, but I don't remember if it cost me anything, because as I was a child, well, children learn quickly, don't they?

INTERVIEWER: Well, normally I don't like to talk about negative experiences, but I would like to know if there is a particular one that you would least like to mention, no, from your school experience, something that you feel has marked you in a negative way.

HIKARI: I think this whole process of being in regular elementary school and having to ask for permission to be there is already negative, right? So yes, I think that in general, I mean, everything is searching for schools, searching for teachers, and also exclusion in the socialization of other children. Everything makes this process negative, doesn't it?

INTERVIEWER: When you finished school, did you feel relieved, and did you ever think anything like that?

HIKARI: I think so, I mean, I felt like, finally, no, I'm done, or something like that.

INTERVIEWER: And with the people I've studied with, you mentioned that you're still in touch with one or that other friend that you had a special friendship with, but I think it's hard, isn't it? To keep in touch with so many people that you've met.

HIKARI: Yes, I have kept in touch with some friends. Yes, some from elementary school... Yes, some from elementary school, well, more from high school, right?

INTERVIEWER: And during this whole stage, the word disability was not part of the language. At no time did it appear?

HIKARI: No. No. I mean, I started to recognize myself as a person with a disability in college. I mean, I started to recognize myself as a person with a disability in college.

INTERVIEWER: And if you could find a simile or a synonym for it? No, not a synonym, but something that would replace what disability means to you, but in school they called it something else, do you recognize any particular language or words? Outside of CEBE, at Básica Regula.

HIKARI: Yes, yes, yes, yes... Like... "Special" or something like that, right? Or "can't see", or "can't see normally",

INTERVIEWER: This word "special". Did they say to you as if it were an attribute? I mean, ah, it's something like "she's special". "Andrea is special. Something like that?

HIKARI: Yes, something like that.

INTERVIEWER: And, when they said something like that, did it bother you, did you not care, or did you say more of the same?

HIKARI: I think I had normalized it. I mean, I guess, as I said, it's hard for me, and in fact I ask myself that myself, right? I mean, it's hard for me to associate the situation to my emotions at that moment. I mean, it's not that I can tell you, I felt bad at that moment. Because I don't... I mean, for example, something that I remember, that is, that one can say that I felt bad, but I don't remember. For example, I remember that, when I was in, I think I was in sixth grade or something like that, just when, at this time when the kids, like they are saying hey, yes, I like such and such a girl or something like that, this... sixth, yes, sixth grade, the last year of elementary school. When you are almost in puberty, right? I remember that one of the children made a comment to me, he made a comment in general, that is, when we were at a table. I think we were taking knitting classes or something like that. I mean, they were some classes that were also like manual activities or something like that. And the kid made a comment like, ah, but I don't think anyone would notice Andrea or something like that, right? And of course, and if you ask me, what did you feel at that moment? I don't remember, I mean, I remember his comment, but I don't remember that I felt anything. I mean, I suppose and I assume that I must have felt bad, but I don't remember my emotions.

INTERVIEWER: Well, it must be quite a difficult thing to process at the time, right? It's quite complicated, complex.

HIKARI: Exactly, or maybe I have blocked it, I don't know.

INTERVIEWER: I understand. So, these kinds of comments it's not that they didn't happen, they did happen you just don't have a special fondness that you remember about it.

HIKARI: Exactly, it's not that I can tell you, oh yes, at that moment I felt bad, I started crying. No, no, no, no, no, I mean, I don't remember it, I don't remember it like that. But, I mean, I do remember, how can I tell you, these moments when... I mean, for example, I remember that sometimes I was at recess and I was alone. I mean, my friends were playing somewhere else and I was alone. But I only have this memory as if it was... as if it happened, that's all, but I don't even remember how I felt.

INTERVIEWER: What kind of games could you play alone?

HIKARI: I mean, no, no, no, no, it's not that I was playing alone, it's that I was alone, I mean literally, I was walking alone and my friends were playing. My classmates, I mean, in the classroom, playing apart.

INTERVIEWER: I understand. I'm missing what I was just... it was on the tip of my tongue. Oh yeah, there's something important I wanted to ask you. Do you feel like there's something that you missed out on in school? Something that you would have liked to do, participate in, or that you were taught?

HIKARI: How? How? I can't hear you very well.

INTERVIEWER: Something you feel you missed out on in school. What you would have liked to have participated in, or what you would have liked to have been offered or taught that didn't happen Have you ever thought anything about that?

HIKARI: Well, I would have liked them to show me this.... I mean, I would have liked them to give me accessibility measures, not from the beginning, they almost never gave me accessibility measures. I mean, they never gave me adapted material, almost never. Some teachers, as I said, but it depended more on the teacher's will. Yes, I would have liked to have been taught that... that maybe there is more like this... on the part of the teachers to pay attention to what is happening, for example, why the children do not play with her. Why don't I provide more inclusive spaces, right? I mean, it's not like letting in students with disabilities and that's it, but your role as a teacher is to provide a space that is respectful of diversity. So, I think there were no such things.

INTERVIEWER: You also mentioned that you practice dance, I imagine it is because you like it very much. Is that something that, when you were in school, you also wanted to do?

HIKARI: No, I mean, yes, but I didn't do it because there was no one to teach me.

INTERVIEWER: But you wanted to, I mean, it was something you knew you were interested in.

HIKARI: Yes, of course, I liked to dance.

INTERVIEWER: And in physical education classes, is there anything in particular that you remember, that you feel like?

HIKARI: I hardly ever did physical education. I mean, I did, but sometimes. But almost not.

INTERVIEWER: Did you have something like a permit, an exception?

HIKARI: It wasn't that I had it explicitly, was it? It was that I just didn't.

INTERVIEWER: You didn't. The teacher didn't require you to do it either.

HIKARI: No. I mean, he demanded it from me, he demanded it from me at times, but nothing more.

INTERVIEWER: Or was the professor inviting you not to do it? No, I don't want to put words that are not the...

HIKARI: No, I mean, it's not like he was telling me "hey, don't do it". He just didn't worry about me doing it.

INTERVIEWER: Ah... And you didn't feel you could do it either, maybe?

HIKARI: I mean, it's just... I don't remember. Something, it was just like... What happened is that, for example, in physical education they did a lot of sports. In my school, in high school I just remember. For example, they played volleyball. So, well, I didn't participate there.

INTERVIEWER: Okay, it was more like.... You guys know what to do and do it. a thing like that?

HIKARI: Exactly.

INTERVIEWER: Sorry if the question was awkward. But I know that just the nutritional issues are particularly difficult when there is no due attention to people. Well Andrea, is there anything that in particular... Is there anything that you would like to add in the interview to close it, that I haven't asked you or that you would like to highlight or mention about what we have talked about?

HIKARI: I think that, as you are talking about imaginaries and this, I think that something I could conclude from this is that I feel that exclusion is normalized in schools. I mean, of course, it's like I said, no, I mean, exclusion is like the norm, isn't it? That I don't participate in the games was like the norm. And of course, if you ask me, have you ever noticed a child questioning it? I don't know, I don't remember if at some point a child, my partner, questioned it. Maybe they did, maybe they just normalized it too, didn't they. So, I think there is a normalization. Ah, for example, I remember that once a classmate made a comment that... what happened is that in the school where I was in the last year of high school, there were many children, even when I was leaving, with intellectual disabilities. So my partner and my classmate said something like, "ah, in this school there are a lot of special kids" or something like that. As if to say "hey, look, our school has several special children" but saying it a bit like a joke, right? So, of course, I feel that exclusion is very normalized, right? I mean, although in my case I was a diverse person who was in the classroom, but in reality this exclusion that I am different was still being reproduced, right? In some schools this did not happen, as I said, I was in fifth grade in a school where this did not happen, where I did participate. I even played soccer with them at some point. So it was more collaborative, wasn't it? But in most schools that didn't happen, didn't it?

INTERVIEWER: Do you feel more identified with the word "diverse" than with the word "disability"?

HIKARI: With both.

INTERVIEWER: Perhaps one complements the other?

HIKARI: Disability is part of diversity, isn't it? Diversity has, that is, several, that is, it is integrated by several communities.

INTERVIEWER: Well, Andrea, I don't want to go over the hour. I'm already running over the hour, sorry for extending the interview by so many.

HIKARI: Yes, I was about to tell you that I had to leave.

INTERVIEWER: Many accidents during the interview, Excuse me. Well, thank you, Andrea. If there is anything pending to coordinate regarding the interview, I will write you a message so we can coordinate the things that are pending, okay?

HIKARI: Yes

INTERVIEWER: And any clarifications that need to be made or that you would like to make to me, we do it that way.

HIKARI: Yeah, it's perfect.

INTERVIEWER: Okay. Thank you very much, Andrea.

HIKARI: Thank you. Take care of yourself.

INTERVIEWER: Have a nice day. Bye.

HIKARI: Bye.