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The [] History of Disability in Mexico

In Mexico there is no structured history of disability as a field. When looking for disability-related information, everything points to the publications by the National Institute of Geography and Statistics¹ (INEGI)— the institution dedicated to making census, population surveys, and analyzing statistical information. INEGI has published several digital booklets on the situation of disabled citizens throughout the country². These booklets start with a short introduction addressing the criteria and definitions used for the design of the surveys, the methodology for information gathering and for the final analysis. In the booklet published in 2013,³ the introduction starts by giving a brief review of the history of disability. Under this section a quick and vague overview of centuries, wars and institutions is chronologically presented and prepares the way for the next chapter on the implementation in Mexico of the updated international standards and the progress that all that allegedly represents for the country in terms of human rights and public policy. After that, the publications focus almost exclusively on the different models and methodologies⁴ used to design surveys, gather and analyze information. Despite being an oversimplified timeline of the models of disability, it's relevance can be assured by the fact that those few pages are frequently referenced in several works regarding disability in the Mexican academic attempts (including my own) to engage with this topic. As useful as it can be to summarize centuries of history into a few

1 Instituto Nacional de Estadística y Geografía (

2 INEGI, disability, publications: <http://www.beta.inegi.org.mx/temas/discapacidad/default.html#Publicaciones>

3 INEGI, *La discapacidad en México, una visión al 2010* (México: INEGI, 2013).

4 Methodologies depart from the UN and WHO guidelines and follow the ICF.

pages⁵, this brief history is reductive and leads to the idea that disability is a simple condition that can only be approached in a single way that evolves through time and leaves behind all the outdated conceptions. But the reasons for that set of changes, and the actual understanding of what the words and models contain, are kept away from the narrative, which instead focuses on how updated the Mexican approach to disability is and how important human rights are. And although human rights are certainly important, it seems unlikely that people will understand where this focus comes from, or why claims for rights are still insistently being made by persons with disabilities. It seems unlikely that people will fully understand what disability refers to with a “conceptual change”, that it has been defined with different words throughout time, and how things named by that word change according to culture, time, and space.

However, if one thing is clear in the simplified history put together by INEGI, it is that disability has always been there. Then, where should we look to if we want to know more or if we want others to know more about it? Where are the particularities that happened before us in this geographical space that now claims to be in alliance with the international lead? Why is it even important to know more about disability in the past? For whom? For what? This essay departs from that simplified history of disability and the absence that it makes present. It thinks toward the possibilities of communicating the nontransferable embodiment that is at the core of disability in the form of History. It claims the need for a History of Disability in Mexico as an archive of knowledge that resides in the overlapping spaces where disability meets *normalcy*.⁶

5 Or as enlightening as it can be for someone that has never had any contact with disability, either because of not being close to a person with disabilities or having no idea of the existence of disability studies, or because of being alienated by ableism.

6 I differentiate *normal* from *norm*, and departing from this I use *normalcy* as a relative everyday-ness that is built by the accumulation of individual repetitions, as something that is inherently diverse.

Following the INEGI booklets, the place to look first is the medical institution. This is a common association, the boundary between disability and disease is still a matter of discussion and their blurry border has been explored by several historians of disability and historians of medicine, seeking to define the limits and contents of both fields⁷. As Catherine Kudlick says, it's hard to tell whether both disciplines are "rival siblings or conjoined twins."⁸ But this tight bond is more an intersection than a union, because there are clear fundamental differences in the approaches and narratives to which each of them serve. These differences range from the assignment of roles, to the modes of documentation and dissemination of the knowledge generated, and can raise questions about the guidelines of distribution, their hierarchies and structures that reveal the system of value in which they are based and the normalizing tools used to perpetuate it. For this reason, a different history willing to address and take into account those issues, the History of Disability, claims itself important and pertinent.

Throughout time in Mexico, different words, such as *lisiado* (lame), *inválido* (crippled or invalid depending on context), *impedido* (impaired), were used to name disability and the ones who embodied it, before the current word *discapacidad* (disability) appeared in the early 90s. But until the 1980s, disability was a domain of the medical and its definition and accompanying vocabulary were embedded in the health-care system. Since the late 1940s there had been several attempts to conceptualize it, measure it and think of its social dimension. During the 1940s there was a shift in public health from an *hygiene* and *salubrity* approach to one of *welfare*. The 1930s had been a decade of changes that started with conservative approaches but found the need to transform because the cities and population

7 For further reading on this topic see Catherine Kudlick, "Disability History: Why We Need Another "Other"," *The American Historical Review* 108, no. 3 (2003): 763-793; and Beth Linker, "On the Borderland of Medical and Disability History: A Survey of the Fields," *Bulletin of History of Medicine* 87, no. 4 (2013): 499-535.

8 Catherine Kudlick, "Disability History and History of Medicine: Rival Siblings or Conjoined Twins?" (keynote address, Social History of Medicine Conference, Glasgow, Scotland, September, 2008).

were growing fast. *Hygiene* speaks of a moral approach related to the idea that what is clean is good, while *salubrity* comes after the urban sprawl and the need to provide services that guarantee good living conditions.

The shift to *health-care* and *welfare* was related to medical services and a more complete approach that included disease prevention in addition to attention; this approach was one that claimed progress through science and technological development. In this context, disability was framed as a physiological problem that led to a psychological imbalance that kept the person from a productive life in society. The attempts to address disability heavily emphasized a rehabilitative approach, that peaked during the 1950s when the General Rehabilitation Directorate⁹ (DGR) was created. The institution started with physical and vocational rehabilitation goals that then became secondary as scientific and technological development were prioritized. During the late 1970s the division between *healthcare* and *welfare* became more evident in the redistribution of disease and disability to different institutions. The DGR would rule health and disease, while disability became a domain of the National System for the Integral Development of the Family¹⁰ (DIF), along with other “vulnerable parts of the population” such as children, the elderly and pregnant women. The 1970s were a transitional decade where the focus on *social development* anticipated the paradigm shift that made possible the legitimation of disability as a category of its own. Disability was more clearly identified as a separate category than disease in the National Invalids Survey of 1982. Despite using a different word, and certainly a different model, than the ones used today, this survey can be tracked as the starting point to address disability as a social category instead of being just another kind of disease.

9 Dirección General de Rehabilitación (DGR)

10 Sistema Nacional para el Desarrollo Integral de la Familia (DIF)

The appearance of the words *inválido* (invalid) and *minusválido* (handicapped) during the 80s mark a breaking point, but another decade had to pass before the word *discapacidad* (disability) and the social model appeared in the map with the creation of the Commission for the Well-being and Incorporation to the Development of Persons with Disabilities¹¹ (CONVIVE) in 1995. This prepared the way for the 2000s' focus on *integration* and *rights*, reflected in the 2005 General Law of Persons with Disability¹². In this context, *integration* spoke not only of medical rehabilitation and access to welfare but also of access to employment, education, urban and architectural facilities, transportation, communication, sports and culture. This approach continued in the 2011 General Law of the Inclusion of Persons with Disability and its 2018 reform. The new concept of *inclusion*, seeks to fully integrate persons with disability to society by establishing policies that guarantee their rights and equal opportunities. *Inclusion* is presented as a counteraction to discrimination.

But in order to be effective, *inclusion* has to come with an acknowledgment of the long history of discrimination, oppression and invisibility that disability has been subjected to. It has to be more of a reconciliation, where access is not the only objective and disabled people are not the ones to be fixed. Inclusion has to be bidirectional and attempt to change the social mindset toward disability; and this is the kind of approach and labor that a History of Disability regards and facilitates.

The History of Disability seeks to focus on different details that were overlooked in the medical setting and the theories of health distribution, and point to where medical history never intended to look. The aim is not only to locate what was understood by disability in a certain historical or cultural context, the criteria to define it and the structures from which the

11 Comisión Nacional Coordinadora para el Bienestar y la Incorporación al Desarrollo de las Personas con Discapacidad (CONVIVE).

12 Ley General de las Personas con Discapacidad, <http://www.salud.gob.mx/unidades/cdi/nom/compil/ley100605.html> accessed 03/27/2020

definitions departed¹³, but also to locate where the people labeled by that word were, what their daily life was like, what activities they carried out, what relationships they were in, what can their existence and their position tell us. The History of Disability advocates for the agency that the medical history denies to its objects of study, and it is based on the understanding of the inherent variability of disabled embodiments, as well as on the embodied modes of production and understanding that variability make possible.

The labor of disability historians starts by unearthing stories, characters and situations forgotten because of not having a space or vocabulary to be named, or because not matching the set of values of a certain time period or society. Compiling all this into a single field is an attempt to restore and to make visible the constituent violence¹⁴ that lead to the absence of an identity in history because its roles, processes and expectations were determined by a vertical structure. That segregating structure lead not only to the lack of representation and access, but also to the appropriation of the dominant narratives by the ones damaged by them, perpetuating the violence and oppression against themselves. Thus, the challenge now is, borrowing the words of Ariella Azoulay, "how to write [a] history that does not partake in preserving the constituent violence, [a] history that is not merely its reiteration."¹⁵

Azoulay makes a call to identify in the archive and in history the moments or events where "other options could have been chosen"¹⁶ to use them as a starting point for a Potential History. This Potential History is one that could have happened if other conditions had been chosen by the authorities, other words stated or other values recognized; it is an imagined

13 Or the ones that departed from the definition

14 I use constituent violence in the sense used by Ariella Azoulay (departing from Walter Benjamin's *Critique of Violence*) to refer to the violence of displacement and deterritorialization that is kept on the structures and contents with which an archive is constituted and disseminated. Ariella Azoulay, "Potential History: Thinking Through Violence." *Critical Inquiry* 39, no 3 (Spring 2013): 550.

15 Ibid., 553

16 Ibid., 551

alternative reality that allows us to rethink both the past and the present because each moment of the present can also be the starting point for infinite potential stories. Potential History reminds us that Other stories and existences are and always have been possible. With this in mind, the endeavor of a new field like the History of Disability is to identify the starting points for Potential Histories of disability and build an archive that includes both, the unseen or silenced histories that did happen and the imagined histories that could have been possible if those breaking points had been recognized before. In this way, the History of Disability could be an accumulation of pieces taken from the most diverse fields and sources, a body made of overlapping fragments that complicated other fields. This is not to separate them from their original places, but to open up new starting points to restore history and re-articulate it in ways that serve as new parameters for documenting the representations and narratives of disability in the future. This attention to the unnoticed intersections can help to build history not as a chronological timeline but as an overlap of stories, events and understandings that can weave into each other. Because in the end, disability is anachronistic. It is more an accumulation of all historical perceptions that continue to coexist and manifest themselves in different ways in the present.

In order to piece together the field of Disability History we must keep in mind the modes of production of knowledge and meaning that only this embodiment can give us. We must think about how to restore agency, what it has meant and what it could mean if it departed from needs and desires¹⁷ stated in first person. The History of Disability not as a field to be instituted, but as an editorial approach¹⁸ to all existing fields, functions as a public

17 Desire as understood by Eve Tuck and C. Ree: "Desire is what we know about ourselves" in opposition to damage. Her definition of damage ("Damage is what is attributed to us by those who wish to contain us") is close to what I understand as Ariella Azoulay's constitutive violence. Eve Tuck and C. Ree "A Glossary of Haunting," in *Handbook of Autoethnography*, ed. Stacey Holman Jones, Tony E. Adams, and Carolyn Ellis (Abingdon: Routledge, 2013), 647-648.

18 Departing from Joseph Grigely's *Editing Bodies*, I understand editing as the process of putting together parts not originally intended to be together with the means of questioning and rearranging the set of values and meanings that those parts stand for. Joseph Grigely, "Editing Bodies," in *Reimagining Textuality. Textual Studies in the Late Age of Print*, ed. Elizabeth Bergmann Loizeaux and Neil Fraistat (Wisconsin: The University of Wisconsin Press, 2002), 60-83.

archive and accessible material for future editing. To understand history as an archive¹⁹ can open up its conventional understanding of format, editorial strategies and authorship, as well as the possibility of activation. Leaving room for formats different than the text is moving away from the values instituted by western tradition and instead appreciating the knowledge that oral traditions, gestural or signed languages, tactile codes, graphic representations have developed and kept within their users. There is also a relationship between formats, its structure and the content they communicate that has to be taken into account when engaging in conversation so that it meets the needs and respects the agency of all parts involved. In this context, the activation is an open invitation to engage in conversations, to keep editing and re-configuring the body of the archive, and with that the future of the real bodies that it represents.

A Disability History is constructed more by uncertainty than certainty, by continuous translations and adaptations to innumerable languages, understandings, forms and scales, by daily tricks and strategies of survival and resistance, by trial and error, by a sharp observation and mapping of the environment that leads to an equally acute awareness of oneself. The challenge of a disability historian/archivist/storyteller is to articulate the difference and specific existence of an embodiment that can only be fully understood by experience. The starting point of the restoration of disability in history lies in a personal reconstruction that involves both the abstract/constructed and the physical/sensorial knowledge we have accumulated through experience, because as Joseph Grigely concludes in *Editing Bodies*: "Texts, as bodies, are extensions of the bodies that create them, and therein lies the mystery."²⁰

19 Regarding the making of an archive, Stuart Hall writes "It occurs at the moment when a relatively random collection of works, whose movement appears simply to be propelled from one creative production to the next, is at the point of becoming something more ordered and considered: an object of reflection and debate. The moment of the archive represents the end of a certain kind of creative innocence, and the beginning of a new stage of self-consciousness, of self-reflexivity". Stuart Hall, "Constituting an Archive." *Third Text* 15, no. 54 (2001): 89.

20 Joseph Grigely, "Editing Bodies," in *Reimagining Textuality. Textual Studies in the Late Age of Print*, ed. Elizabeth Bergmann Loizeaux and Neil Fraistat (Wisconsin: The University of Wisconsin Press, 2002), p 82.