

**It's Like She Had Never Existed: The Family Story
and the Assembly of Disability**

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Figure 1 Coquis, 196?. Photograph of a girl in a field of flowers. She stands slightly bent forward with her arms a little open and looks at the camera with a fearful stare. Image courtesy of Ana García Jácome.

It's like she had never existed. We never go to the cemetery to see her; they never tell her childhood stories or her achievements. The only thing that is known is that she was sick. I only know what she looks like because of the picture in our grandparents' bathroom, where she looks normal, but fearful. Of the several family albums of photographs of parties and picnics, she only appears in two when she was very young and someone is always holding her up, forcing her, pointing toward the camera as if she were not able to find it by herself. The only frequent reference to her name is when someone mentions the room she occupied, which was built specifically for her: the room at the back of the house, the smallest, which after being "the room of Coquis" was "the room of the children," my room. Once I saw a picture of her, already adult, in bed, with all the appearance of a conventional sick person, and I accepted her like that and saved that picture in my imagination, just as everyone else did. But that imagination was an incomplete construction; it did not say that her deterioration, both physiological and within the family history, was caused by cerebral palsy, that the first signs of it were a few months after she was born, that she stopped walking when she was nine or ten years old, that she died the year that I was born. Nor did it say if she felt like everyone describes her or if she had the chance to control her representation in the photos, if she wanted to go out more often and they did not let her, or if she preferred to hide in the backroom. Does that happen in all families that have sick people? Who decides who is a sick person? What would we see in the images if we didn't have the story? What would we find in the story without images? Why does it seem like she never existed? What is it that everyone wants to erase? Why?

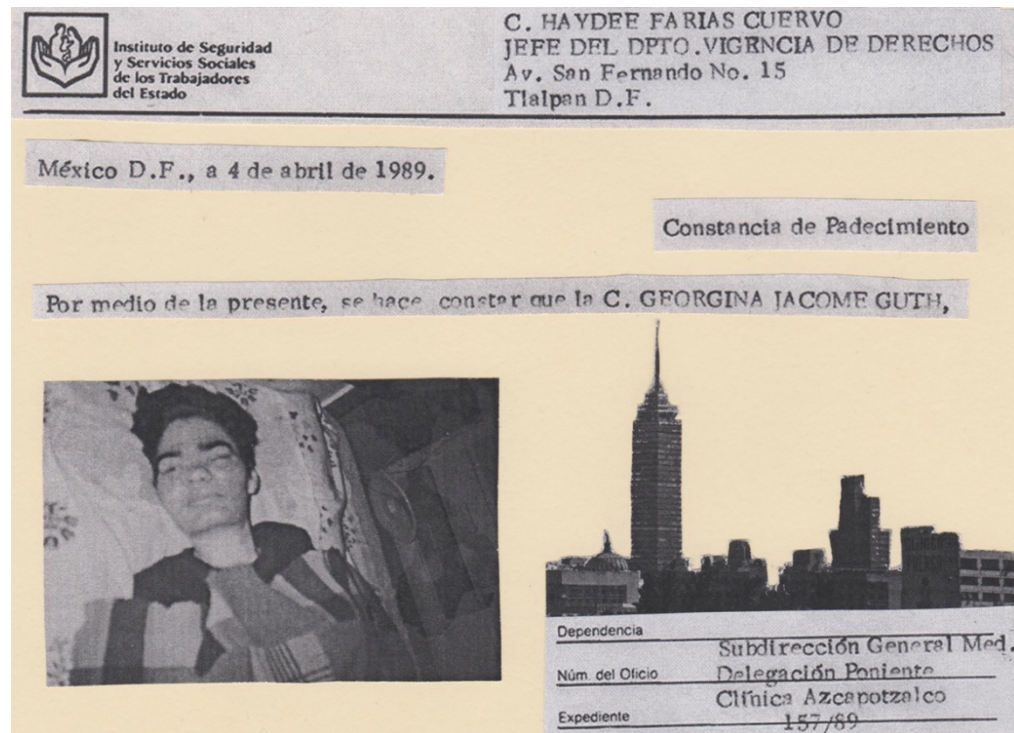


Figure 2 Adult Coquis in Mexico, collage, 2018. Image description: Collage of pieces of documents with Spanish text and black and white photographs. At the top is a header with a hospital logo and address. Below it on the left, a line reads, “Mexico, April 4, 1989.” The next line starts on the right: “Certificate of Impairment.” A third line follows with the name Georgina Jacome Guth. At the bottom left is a photo of adult Coquis in bed. At the bottom right is a photo of Mexico City and a file label. Image courtesy of Ana García Jácome.

In the 1960s in Mexico, there was no concept of disability. Its translation, “dis-capacidad,” is a relatively recent word that started being used during the 1990s under the influence of the United Nations. For over fifty years before that, “inválido,” closer in etymology to “invalid” but similar in meaning and intention to “cripple,” was the word of generalized use both within the medical institution and outside it in everyday life. In 1953 the Directorate of Rehabilitation was created to care for the country’s “cripples,” since numbers had risen because of the polio epidemic of 1946. This eventually led to the construction of rehabilitation and special education centers in different states and an innovative hospital in the center of the country. In 1986 the Law on the National System of Social Assistance defined the family as “the cell of society that provides its members with all the elements required by the various circumstances of its development” and therefore makes the family the priority for social assistance provided by the State. This emphasis on the family as the center of the development of all individuals not only makes it a beneficiary of services but also explicitly makes it responsible for the

care and well-being of all its members, including and especially the “cripples.” Rather than being a progressive move, this further reinforced caretaking labor as a duty of the family, making it accountable for its disabled members and building a rhetoric of disability as a burden. In addition, it confined disabled people to private lives within the family boundaries, as if disability were a merely personal problem concerning only the people close to the ones who embodied it. However, this insertion of disability in the field of social assistance was a step toward separating the disabled from the purely medical context that had contained them until then. Years later, in 1995 the National Commission for the Welfare and Inclusion of People with Disabilities was created to guarantee the full integration and development of people with disabilities. It wasn’t until 1995 that the concept of disability began to be used and until 2005 that the rights of the people with disabilities were explicitly addressed in law: the General Law of Persons with Disabilities.

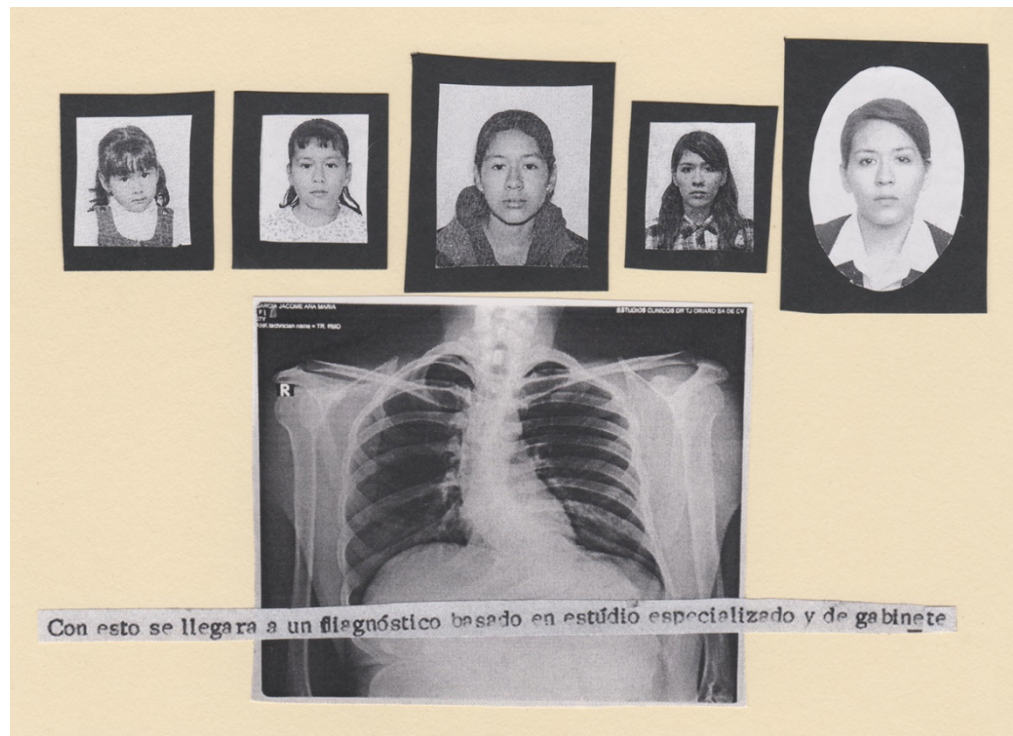


Figure 3 Ana growing up, collage, 2018. Image description: Collage. Five I.D. photographs are framed in black and aligned horizontally at the top of the collage. The person in the photographs is me at different ages: in the first one I was about 4 years old. In the last one I was 25. At the bottom is an x-ray of my spine overlaid with a line of Spanish text reading, “A diagnosis will be made based on specialized tests.” Image courtesy of Ana García Jácome.

I grew up listening to the family being sorry that someone was sick or had become disabled. “Poor thing, they’re screwed.” “Life’s twists and turns . . .” I learned that the sick and disabled suffer and complicate family relationships. I understood that they become burdens for their families and that they need to be taken care of, but also that we must applaud their inhuman efforts to continue living, because nobody wants to live like that. But as time passed, all this made me more and more uncomfortable. I understood that I fit in that pity and that hollow admiration. I looked like those described, but I didn’t feel anything like them. Suddenly every time I heard the family talking about other sick or disabled people, I would only think: was I a burden for the family? Did everyone believe that my life was empty and continuous suffering? Was that how other people talked about me and my family? But above all, how could my family talk like that if they had me there and knew that disability was not like those conventions. But did they know? And besides, before me, Coquis was there.



Figure 4 Coquis at a family picnic, 196?. Image description: three black and white photographs in a row. They all show a young Coquis being held by arms and hands. The faces of the people grabbing her are cut out of the frame. Image courtesy of Ana García Jácome.

I started this project looking for the complete story of Coquis. I had never been so interested in her despite the fact that when I saw her photos I somehow saw myself. The photos did not show her movement or her sounds, just frozen moments. Stillness left a lot of chance for the imagination to assign a feeling to her countenance, to imagine her relationships to others based on their gestures and positions. I could not be certain about the places or the situations that the images showed, but I recognized the hands that held and guided her, that constant watchfulness and overprotection. I guessed the words of the adults in the pictures even though the images were silent. “You come with me.” “No, over here.” “You cannot.” “Be careful.” “You’re going to fall.” I’ve heard those phrases all my life, I suppose she did, too, and I looked at the photos in hopes of finding a complicity, in hopes of finding something that told me that she also hated them, that she fled from them and insisted on going down the uneven road, falling a thousand times but getting up in all of them, seeking to escape from the constant gaze and words that were aimed only at her. I always wonder if other people that haven’t had our same experiences read the images in the same way. I think they don’t. Maybe they just find curious details or weird poses. Maybe they are close to some disabled person and recognize the gestures. But I am almost certain that disability can be invisible in still images of the everyday. Sometimes when we don’t move, or make sounds, we can pass as abled.



Figure 5 Pap with video camera, 199?. Image description: Color photograph of my grandfather standing inside a house. He is holding a video camera pointed at the photographer and smiling. Image courtesy of Ana García Jácome.

Sometimes I think that what I have been told about her has influenced the way I see the photos. I try to look for strange features that show her difference or reveal that she was not “normal.” I try to force that girl from the images to enter a story that is not hers. I wonder if she recognized herself in those photos and in those videos. But recognizing oneself in photos and in videos are two different

experiences. Photographs capture a single moment but leave a lot unseen. Videos, on the other hand, replay scenes with the exact same movement through a space and a time lapse. In photographs, the movement behind the moment depends on memory and imagination, while in videos it becomes the unavoidable reality. This difference makes me think of the terror I felt when I first saw myself in a video that my grandfather had recorded of our vacation. I did not recognize myself in that girl who moved strangely. My body felt normal, but the video made me think that the body on the screen was making an extraordinary effort to take each step. At that moment, all the looks that followed me constantly on the street and everywhere and that I had never understood made sense. From that day on, I anxiously avoided video cameras. I avoided appearing in the frame, and when I couldn't help it I tried to remain motionless, to look normal. Every time my grandfather projected videos of vacations and meetings, I looked forward to any hint of my appearance to leave the room or turn away, or to distract everyone. I did not want to feel that lack of identification with my own image again, although I experienced it all the time. But neither could I escape the documentation of family moments.



Figure 6 Ana with camera, 2016. Image description: Color photograph of me holding a camera up to my face. Image courtesy of Ana García Jácome.

I got my first camera for Christmas when I was eight. Since then I have been accumulating images that have served different purposes throughout my life. I had a phase where I only photographed landscapes without people; later on I photographed objects and then people mostly. When I bought my first digital camera, I photographed everything around me to the point of annoying my family members. I rarely appeared in my own photographs until I had my first cell phone with a camera, but even then in most photos I am hiding behind the lens, as if I'm photographing the action of taking the photograph rather than my portrait. Once in a while I look back at all the photographs and try to identify the feeling that drove the gaze, the needs behind documenting certain things. While most of my early photographs also ended up in the family album, with the typical organizational method of birthdays, vacations, and weekend activities, the later ones were an exercise of awareness of my surroundings and myself.

Lately I look more at photos that I didn't shoot but my family members did. I try to answer the same questions. I wonder if they thought at all about how others would read their stories and the way they were represented. I wonder if it crossed their minds that this set of images would become an archive of stories and memories, whose order and hierarchy of visibility highlights the traditions, family values, and relationships of its members. But the images also show activities, relationships, objects, and poses that allow them to be located in broader contexts like culture, class, or geographic location. The images that we chose to enlarge tell what we value the most, like those wedding pictures of my grandparents and my parents.

The images we chose to frame tell how we want to be looked at by whoever visits our home, like the photos of the places we've traveled to. The images we discard or keep secret or keep safe tell our priorities, like the portraits on my grandma's nightstand, protected by a glass but hidden under the clock and the lamp. Family archives are not only subjective containers of personal stories and memories—they are indexes of trends, contexts, sociopolitical and economic relations. When looking closely at the photographs, you can identify the roles of the family members. Their clothes or objects reveal their epoch, the place they were in, and their social status. Their selection and display show what they want to remember and how they want to remember it.

discapacidad

1. f. Condición de discapacitado. *Percibe una prestación por su discapacidad.*
2. f. Manifestación de una **discapacidad**. *Personas con discapacidades en las extremidades.*

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Figure 7 Definition of “discapacidad,” accessed 2019. Image description: Screenshot of the definition of “discapacidad” from the online dictionary of the Royal Academy of Spanish Language.

After listening to the stories that everyone told me about Coquis, I felt that something was wrong. That I was wrong, that we were not the same, that I could not compare my disability with hers or claim her needs and ideal relationships based on mine. That my criticism of the family for not mentioning her should also be a critique of my absence of questions and my assumptions about her existence. And yet, we both fit the same word: disability. A word that names a wide variety of bodies and minds that are somehow different from the standard. A word that despite the connotations of its translation into different languages is also instituted as the “right” one, the one that corresponds with the current societal model that tries to be a little kinder and include those who have been excluded and deemed unworthy. In spite of that, it was a word that didn’t appear much in my family’s stories. It was an invisible connection between us that other members intuited in my interest in Coquis, but never came to state. It was a word that they avoided and tried to compensate for with other positive words, as if the word *disability* itself could not be positive in any way or context. It was a word that always directed the conversations, despite being mentioned only a couple of times. But it was also a word that was unknown until two decades ago and whose predecessors, “inválido” (invalid, cripple), “lisiado” (lame), “disminuido” (diminished), “impedido” (impaired), were obviously negative. “Discapacidad” was meant to be the word that broke with the conventional language of the past and provided all Spanish-speaking countries with the vocabulary to participate in the international conversation hosted by the UN. But a lot of people still don’t know this, and in the everyday the past words still overlap with the new one. Is this because people are so used to the old words that they forget to use the new one, or is it a refusal to accept the new framework that comes with the word? How is the permanence of the past words influencing the rejection of the new word? Or is it that the word doesn’t matter, what it names is what they do not want to say?

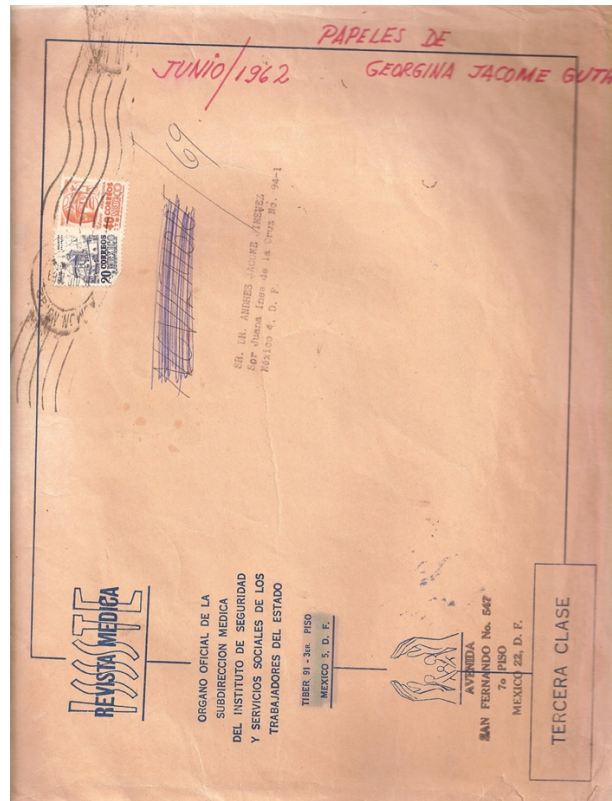


Figure 8 Folder of Coquis' documents, scanned in 2018. Image description: Scanned old folder from a medical magazine. It has two stamps, an address, a handwritten word crossed out, and the printed details of the magazine. On the top of the scan is a red handwritten note: "Papers of Georgina Jacome Guth, June 1962." Image courtesy of Ana García Jácome.

And yet, the photos did not show everything they told me, only a part of it: her frozen childhood, her happy times, when she was able to be part of the outside world. And then she vanishes: it is like she never existed in any other age. There is a part of her missing adulthood partially documented by papers: birth and death certificates, hospital paperwork. It also tells a different story, one that contains words, dates, and names that no one else used, a story that is stored in a different space than the album, like another story, one that should be kept in a more traditional and formal file. But despite this story being an impersonal one, all the administrative documents that form it also tie it to a broader social context; they are what proves her existence and her disability to the State, what makes her eligible for health care and welfare, what grants her certain citizenship status despite her invisibility in society. The documents prove that hers was not an isolated story, that similar but not equal experiences and embodiments exist throughout the country and have their own paperwork but also their own families, photos, and stories.



Figure 9 Coquis and Ana as children, 196?/199?. Image description: Two photographs side by side. On the left is a black and white portrait of Coquis. On the right is a color portrait of me. Image courtesy of Ana García Jácome.

And then, there is my own story, the one I am putting together after breaking apart the others. The one that departs from my own territory or the several geographies that intersect in the territory of my body. My whole experience and knowledge were built at home, by that family that carried the ghost of disability but also by a country that didn't address disability as a separate identity until the 1990s. I learned about my body from the Catholic stories that promised to reward pain, the constant stares that followed me in public spaces, and the bumpy streets that made me stumble every day. But I also learned from observation, from reading, from relating to others and listening to stories that didn't include disability but that helped me identify systems of oppression. When I came across disability studies, I avidly read all those words that provided vocabulary for articulating my everyday thoughts and experiences more cohesively, making them stronger as they were placed in a wider social and economic structure. But the vocabulary was not in my language, and the structure described in those words was somehow not the one that surrounded me. After my first enthusiasm and desire to translate, I spotted the hierarchies of language, citizenship, and education behind the production of knowledge and how its immediate acceptance implied submitting to an English-based academic system that theorized and represented First World experiences. I spotted my own place in those hierarchies as someone privileged enough to access foreign language and then live in foreign land.

Translation seems like the obvious way to take something we admire and share it with others. However, the reading and understanding of the translated content depend on the context and background of the readers as much as they do on the articulation of the pieces, and this is easily overlooked. Now I see my tendency for translation in my first approach to Coquis, as if I from my own disability could translate hers, take her story and put the pieces together from a distance. But as I dig more into her story, I realize that I need so much more knowledge of her surroundings, and the surroundings of her surroundings. Doing this research doesn't allow me to reproduce her story in my own time and my own surroundings but lets me make connections and understand processes. I think of translating languages as a similar process. The experience of disability in a certain language is determined by the geography, culture, and set of regulations and benefits that exist there and that are articulated with that vocabulary. While certain words are instituted as equivalent by international conventions trying to set standards, their connotations in different languages reinforce the complexity of translation.

Translation doesn't take away what has been embodied; it just adds layers. What one does with the accumulation of layers is a different thing. Some choose to bury the deeper ones as past lives left behind. I choose to excavate my past lives and recuperate the traces of my previous selves. By collecting and repurposing images, documents, and experiences I intend to use memory and embodiment as archival strategy. When disabled bodies are absent from history, or contained by institutional language and paperwork, centering their experiences and honoring their memory, making visible all the layers that complicate their existence is the way to claim our place in the present and the possibilities of our future.

Artist Statement

My work explores how disability is conventionally represented and daily experienced, as well as the differences and gaps between the two. The leading threads of my work are disability and narratives. Through fictional narratives, my early projects explore my own body, its shape and movement, and the traces it leaves on the objects and spaces that surround it. My recent work focuses on family stories and looks at how disability is perceived within the household and remembered through generations. This practice is concerned with how disability is historicized and represented by governmental institutions. It departs from archival research and, recuperating the drive of my early projects, intends to make room for the everyday stories and experiences of disability left out of institutional narratives.

Projects like “It’s Like She Never Existed” contribute to a growing field that compiles the experiences of disability in the Latin American territories with languages and realities different from the ones mainstream English-based disability studies portrays. My research focuses on my country, Mexico, and on the relationship between history and ways of seeing and naming: how we identify disability by visible markers, how we relate to it, how we name it, how the words and actions toward it have changed over time. The goal of my work is to raise awareness about how words and actions perpetuate oppression, so that the need for counteractions in the everyday becomes clear.

My practice moves between mediums and materials. I use drawing, writing, and photography, but I also edit and re-purpose found materials, as I am interested in weaving together reality with fiction to imagine possibilities. In the end, my work is a collage of different narrative and material pieces, where writing entangles with the visual, where documents are pulled from the everyday and from institutional archives. I bring together all this in videos and publications which both stand alone and coexist in space as installations.

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Ana García Jácome is a Mexican visual artist. She holds a BFA from the School of Arts and Design of the National Autonomous University of Mexico and an MA from the School of the Art Institute of Chicago (SAIC). She has been a grantee of SAIC, Fundación Jumex Arte Contemporáneo, and the Young Creators program of FONCA. Her work has been part of various exhibitions and screenings in Mexico City and Chicago.