

Los mundos de TITA (The worlds of TITA)

Tita, my older sister is the protagonist of this project. However, it could be any of us. Tita appears in some of the photographs, she is also the author of the drawings that are part of this project. Every picture opens a door where we can enter and exit at different places; they are a passage through different emotional and sensory states.

I would like to invite you to read the following text, written by my father about “Los mundos de TITA”.

Tita is my first daughter; she is now 30 years old.

A few days after her birth, she presented no common symptoms; she clenched her fists, bowed her head, and suddenly, her body lost strength. These symptoms were repeated several times a day, so we decided to take her to the doctor. A general physician referred her to a neurologist. From there it was a long journey, where professionals from different cities diagnosed her illness as epileptic seizure spasms. As parents, we lived this time in a state of shock and we were not able to digest a reality that we did not understand and it overwhelmed us.

The ethology is not now important. Electroencephalograms and multiple tests concluded that Tita suffered from the West syndrome, which consists of a serious and rare brain disorder that generates short axial muscle contractions. This produces psychomotor retardation with pervasive development disorder. Some neurologists agreed that the syndrome later degenerated into the so-called Lennox-Gastaut, which is a childhood epileptic encephalopathy with mental deterioration and therapeutic resistance of great severity. Tita would need much medication for her entire life, and rigorous full time attention.

Tita's condition truncated many of our life projects. However, two years later we decided to have Fabiola. These two girls grew up together until Fabiola turned 5 years old. By then, who was the younger sister became the oldest. Mentally Tita stayed at the same age; she will always be our child. Since then, our communication is based on hugs and deep looks. Her fragility and hyperactivity are an incentive for us to take care of her without any rest.

Fabiola Cedillo (EC)

STATEMENT

Fabiola Cedillo's Los Mundos de TITA is part loving homage, part fever dream. The series follows her older sister Tita, who was diagnosed with a rare brain disorder as a child. Now in her thirties, Tita remains in a childlike state, in need of her family's full-time care and attention. “Our communication is based on hugs and deep gazes,” writes Cedillo's father in a statement preceding the series. “Her fragility and hyperactivity drive us forward into taking care of her without rest.”

The series sets fragments of girlhood alongside surreal visions. In one image, stickers dance along the wall of a brightly lit bedroom awash in pink. In another, a grown man crouches naked and wet in a plastic washbasin far too small to hold him. Cedillo presents the series in diptychs: in one pairing, a white horse looks out from behind the metal bars of its stall. From behind the invisible confines of her disability, so too does Tita look out at the world.

Communication is a challenge for Tita and her family. Punctuated by dense shadow and the absence of information, Los Mundos de TITA conveys Cedillo's frustration and longing to connect with her sister. Be it a mural half-painted white, or Tita's back to the camera, Cedillo's photographs remind us that pieces of Tita's world remain just out of our grasp. On the other hand, they are also brimming with love, humor, and irony. Cedillo made the important choice to include her sister's

drawings in the work; they're perhaps the most poignant images of all. Alongside portraits of Tita holding her cat, each drawing is an emotive message authored by Tita herself.

Los Mundos de TITA is a nuanced portrayal of someone who faces communication barriers, but whose expression is limitless. With tenderness, it also maps the relationship between sisters who, despite speaking disparate languages, are inextricably connected. Cedillo reminds us that Tita could be any of us. "We all [live] life between reality and fantasy, between dreams and nightmares. We're all fragile and strong, each with our particular limitations," she writes. In a visual landscape where the lives of disabled individuals are seldom pictured, spending time in Tita's world is an extraordinary experience.

— *Katie Booth*

About Fabiola Cedillo

Fabiola Cedillo works with human beings and their condition, and is interested in their emotions and actions, as well as the context in which they develop.

In 2017, Cedillo created AULA, the first analogue laboratory and photography school in Cuenca, Ecuador. She is the cofounder of FOTO-ALBUM, a platform for photography promotion in Ecuador.

Cedillo was 1 of 5 finalist Aperture Portfolio Prize 2018, has been nominated to Joop Swart Masterclass 2018 and 2019 by World Press Photo, awarded the New Generation Prize in 2017, Pamapa Energia FOLA M4C and British Journal of Photography Portrait of Britain in 2016. Finalist, "PRIX LE BAL of Talents jeunes creation photographique 2013" Paris, Francia. Se was selected for residency at the Festival de Photographie de Deauville at "PLANCHE(s) CONTACT, France 2013.

Her work has been featured in various international festivals, including Copenhagen Photo Festival; SAN JOSÉ PHOTO, Uruguay; PA-TA-TA Festival, Granada, Spain; and Encontros da Imagem, Braga, Portugal. In 2016, Cedillo self-published her first photobook, titled Los mundos de TITA, which was shortlisted for the Latin American Photobook Award, Mexico City; Photobook Bristol, England; Belfast Photo Festival, Irlanda; and the Kassel Dummy Award, Kassel, Germany.