

Forgotten and neglected, the hidden disabled children of Uganda

Many children in the East African country have never been diagnosed with a specific condition but they are disabled – and that makes them a target

Beau Donnelly

The corrugated iron door unlocks from the outside and pushes open slowly. A girl in a faded dress and green sandals looks up as the unforgiving African sun pierces the room. She doesn't move. Sitting on a wooden chair, she is tethered by a length of thin cloth, fastened tight around her wrist.

Catherine is 12 years old. Small for her age, she looks even younger sitting in the dark, hands resting in her lap. For more than half her life she has been locked inside this hut, no bigger than a garden shed. She sleeps on the concrete floor without a mattress, between sacks of dried cassava. Chickens she shares the storeroom with roost in baskets.

"This should not be a normal thing," sighs Fred Alimet, a pastor in this swathe of countryside in Soroti District, in Uganda's east, where farmers live with their families in mud brick huts built on terracotta dirt. "But because this child has a disability she is being hidden."

Pastor Fred wipes the sweat from his forehead and kneels down to loosen the cloth around Catherine's arm. She recoils, so he calls in her mother. Not a word is spoken as she unties the tether, and Catherine stands and walks outside into the sunlight.

The mother, Sarah Akello, does not live here. Akello's husband rejected Catherine because she has a disability, believing her to be cursed or another man's child. "The father doesn't want to see her," says Pastor Fred, translating Akello's words. "The father is asking the mother how she got this child. The other seven children are okay, but this one is having a problem."

Akello explains that Catherine is locked away here, on her eldest son's plot of land, because of what will happen to her if she wanders off. Like many children in Uganda, Catherine has never been diagnosed with a specific condition, but she is disabled, and that makes her a target.

"Sometimes when she leaves here she gets beaten from outside, she gets abused," Akello says. "She has been beaten many times." Standing three feet away, absent present, nobody speaks to Catherine. When the case workers leave she is returned to the hut, the piece of cloth with small blue flowers tied back around her wrist.

Socially outcast

In Uganda, people with physical or intellectual disabilities are often considered a burden; unable to work, or to learn. Stigma is fuelled by beliefs that people with disabilities are cursed. Some believe disability is caused by sin; a promiscuous mother or the wrongdoing of ancestors. Some believe disabled people are possessed. Disabled children rank among the most socially outcast and vulnerable in Uganda.

They are more likely to be denied healthcare, less likely to go to school, at higher risk of abuse and sexual violence. Across the country, these children are hidden away, warehoused out of sight, or worse.

"There has been a lot of resistance towards these children over the years," says Stephen Kabenge from Embrace Culture, a not-for-profit that works to find hidden children. "So many organisations are trying to fight it, but it is not one man's struggle." Embrace Culture houses and schools 20 disabled children and young adults at its headquarters in Entebbe, a gated oasis an hour's drive from the capital of Kampala.

Today, Kabenge is travelling across town to check in on a single mother and her daughter. Nearing the house, he sums up the plight of many parents, mostly women, struggling to care for disabled children alone. "She has told me she is just waiting for this child to die," Kabenge says as the van comes to a stop.

The house is in Lugonjo, a densely populated slum near the edge of Lake Victoria. Outside, a bony middle-aged woman is slumped against a wall gripping an almost-empty bottle of waragi, a home-brewed liquor. The building has two small rooms. No bathroom or kitchen. Food is prepared outside, next to a car tyre filled with pots and plastic containers. Piles of laundry the mother earns a living from washing hang over the bed. A children's alphabet chart is stuck to the wall across from a calendar that hasn't been changed since August, 2018. There is one window, a single metal bar running down the middle.

The scars over Salma's body tell the story. She is almost 10, but totters like she is still learning how to walk. She stumbles forward, then backwards, always about to fall. Her mother, Zubeda Nono, steadies her with a hand under the armpit. Then Salma wrestles away, jerking off the walls, or writhing on the chipped floor. Her eyes are vacant, unblinking.

Salma has sickle cell disease and epilepsy. Health workers believe she also has autism, but say this is not being treated because of a shortage of screening and diagnosis services. She is partially deaf, blind in the right eye, and mute. Nono fetches two thin, soiled mattresses and drops them on the floor to demonstrate how she softens Salma's falls when she goes out. Using a large stone, Nono secures the lower half of the door shut from the



outside, leaving the top part open so neighbours can peer in to check on the child. The mother-of-four knows she shouldn't leave Salma alone, but this was her routine when she went to work until her daughter was six. "I'm doing a good job," Nono says matter-of-factly, "because the child is still alive."

On paper, Uganda is one of the success stories out of Africa. Rocketing economic growth means fewer people live below the poverty line. Child deaths are down. Immunisation rates are up. There's more clean drinking water than ever before, and people are living longer. But specialist medical services across the nation are in short supply.

Uganda has a population of more than 40 million people and just one national referral mental health facility, an overcrowded hospital in the capital where children are jammed in with adults. The void left by thinly spread disability services is filled by traditional healers, witch doctors and crooks.

Advocates say reliable government data on disability rates in Uganda doesn't exist, not to mention support services. Michael Miiri, a disability rights advocate and consultant who used to work for the government, says the second major challenge is culture.

"Many people, including the parents, haven't accepted these children to the extent that they don't see value in them, and they're not giving [them] the basic needs like any other child," he says. "This becomes a challenge because a child grows in a state of self-denial, with no support,

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with no love from the parents and the community."

If a disabled child is lucky enough to go to school, chances are that the resources needed to help them simply don't exist. "There's no special arrangement or special grant that is set down to support these children," says Miiri. "If they don't have the money or the resources of information, this child will stay as they are. They cannot access drugs. They depend on non-government organisations."

The trickle of support that did exist has almost dried up. The coronavirus lockdown has thrown up more hurdles for disabled children; transport and food have become more costly, life-saving drugs more difficult to access. Miiri and others say there has also been a spike in reports of sexual abuse during the pandemic. "They are really very much suffering during this period," he says.

Pregnancy
In the waiting room of a small health clinic outside of Kampala, two heavily pregnant women sit on white garden chairs under a poster advertising services to help with fertility, menstruation and changing a child's gender. They are waiting for traditional birth attendant Ruth Nakimera, a 71-year-old with cropped grey hair who wears colourful dresses with flared shoulder pads.

Nakimera ushers one of the women into the back room. The heavily pregnant 25-year-old woman lies on a crumpled, plastic-covered mattress. Nakimera checks the baby's position with a gentle rocking manoeuvre. She presses her ear to the woman's abdomen, her version of a stethoscope, to hear the heartbeat. Then she turns her attention to the mother, pulling her lower eyelids down to read her blood levels.

Nakimera has seen it all. She remembers delivering babies with clubfoot. There have been others with Down's syndrome and spina bifida and, recently, one with partially formed arms. Parents of older disabled children seek out the help of herbalists like her, believing them to be mad or bewitched. "Most times they show a lot of grief," Nakimera says through a translator, "because by the time they run to me they are already worried that

something is not going right with their baby."

When she encounters a baby with a disability or birth defect, Nakimera is careful. She never tells the mother too much, right away. "I have a past with that," she says. Many years ago Nakimera's grandmother delivered a baby with a cleft lip. After the birth, Nakimera says, her grandmother told the mother her child's upper lip and nose were split. "The woman immediately told her, 'I cannot raise such a baby, please end its life.'" That child was raised by Nakimera's grandmother until the age of six. "Ever since then," Nakimera says, "when I find something wrong, I will wait for some time and then deliver the news, and give ways for how the parents can help the baby."

Many people in Uganda told stories about so-called "mercy killings" – the practice where parents abandon their children or violently end their lives. Several parents recounted being told by family and friends to throw their disabled children into the communal pit toilet, withhold medicine or poison them.

In 2018, the European Parliament passed a resolution condemning the ritual killing of children and newborns with disabilities in Uganda, and called on authorities to provide more support to families. But such is the shame and secrecy shrouding disability here, the incidence of the practice is impossible to measure.

Uganda has passed a series of laws and signed international treaties designed to protect the disabled, including becoming one of the first countries to ratify the United Nations Convention on the Rights of Persons with Disabilities. But these public declarations chalk up to almost nothing in the lives of the parents fighting to keep their kids alive, the hidden children, and the workers committed to helping them.

While there has been some progress in access to education and healthcare, many disabled people continue to live on the abyss, with report after report drawing the same conclusions.

The rights and needs of disabled people are "often ignored", said one of the unions representing disability groups. They are particularly at risk of "multiple forms of violence, abuse, neglect and exploitation",

said another, by the United Nations International Children's Fund. A 2016 United Nations report, produced almost a decade after Uganda signed the disability convention, described in one sentence the positive measures the government had taken to promote the rights of disabled people, then detailed in 14 pages more than 50 concerns.

It's a cycle with which the staff at Embrace Culture are all too familiar. The histories of the children at its centre are among some of the most harrowing: a girl with Down's syndrome who suffered horrific sexual abuse; a boy whose ankles are scarred from years of being shackled with chains; a boy with autism who spent his days tethered to a tree.

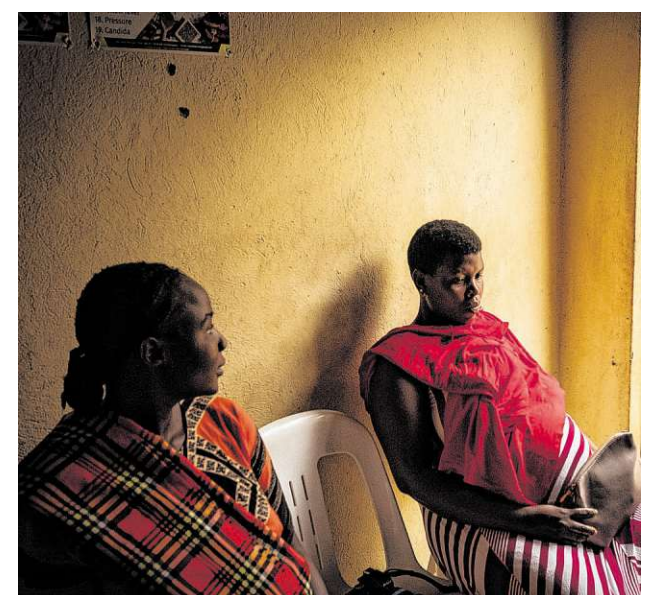
Less than a kilometre from the storeroom in which Catherine is tethered, disability workers found another boy. Silas is locked inside a thatched-roof hut, tethered to a heavy log by rope and ripped cloth. A mosquito net with fist-size holes hangs over a thin piece of discoloured foam on the floor. He has one toy, a ball made from tightly woven plastic bags. The door is tied shut from the outside, where the world goes on without him.

'What is this?'

Silas' parents are still together, a rare occurrence health workers credit for the boy's overall satisfactory health. His mother, Betty Lolu, knew something was different when he was born. "I was asking what is this? What am I producing? Is this a human being? I thought God has given me a different thing, not a child," she recalls.

"I was only waiting for the child to die, but the child did not die. When Silas got so sick I took him to the [health] clinic and they could not help. They said to take him to the hospital. When we went there they said his heart has a hole, only one part of the heart is functioning. They told me they could not help. They gave some painkillers and said to take him back home."

Silas' father, Richard Okodel, says most people in their community told them to take him to the witch doctor, but as Christians they never considered this option. "At times, Silas would get so sick some people would say to just kill him instead of being disturbed day in, day out, by a child who will not get better," Okodel



■ Clockwise from main: Nono and her daughter Salma peer outside their home as a neighbour's child looks in; Pastor Fred Alimet buttons up Silus Odii's shirt after releasing him from being tethered inside; students at the Aamanyi Centre prepare a plot for planting during their agriculture class; Nalule Hamirah, nine months pregnant, and Haddijjah Nabweteme, eight months pregnant, at Ruth Nakimera's clinic in Kabaale, Entebbe. PHOTOGRAPHS: CHRISTOPHER HOPKINS

Asked if they had ever received any support from family, neighbours, community or the government, Ilolu slowly shakes her head. "Nobody," she says. It was only earlier this year that Ilolu and Okodel learned there was a name for their 10-year-old son's mysterious condition: Down's syndrome.

Okodel says they started tying Silas up and locking him in the hut when he started walking, at the age of five, because neighbours, both adults and children, beat him bloody. Pastor Fred says grassroots education is crucial to combating the child disability crisis. "To teach them about the rights of these children," he says. "Most people look for equality, but in Uganda it's more about survival." In this region alone, Pastor Fred says, there are at least 300 other children hidden away. "Most of these children are on ropes or chains. When I find it like this I don't like it."

The pastor asks Silas how often he is tied up. "He says a long time. He says, 'I'm always here.'" He unties the tether from Silas' wrist and lets it drop to the floor. Then he smiles at the little boy and takes his hand. "I am telling him he is handsome, he is good, he is not supposed to be tied like that."

What did he say? "He says, 'Thank you.'"

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