

A Short Life, a Long Lesson:

What My Nephew Taught Me About Disability and Dignity

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BEFORE YOU READ: This article has some hard, technical words in it. What strategies do you use when you come across this type of word?

Born with Many Difficulties

My nephew Benício was born in Brazil in 2019, and from his very first breath, he began a fight most of us will never understand. He was born with breathing difficulties that kept him in an incubator for a week. He had extra fingers and toes, which made the doctors suspect that he had a syndrome. But they didn't investigate further.

At two months old, he had his first seizures. That moment marked the beginning of a long and painful journey — one that exposed not only the fragility of the human body, but the many failures of our society in how we treat people with disabilities.

More than a year and countless hospital visits later, Benício was diagnosed with 1p36 Deletion Syndrome — a rare genetic condition that causes developmental delays, epilepsy, and a range of physical and intellectual challenges. Some years later, he also received a diagnosis of Lennox-Gastaut Syndrome, a severe form of epilepsy. Over time, he suffered many seizures and had developmental delays.

We Advocated for Him to Get Proper Care

Getting access to care was incredibly difficult, even though we had private health insurance. Therapies were denied. Specialists refused to take his case. Many simply said they had no experience with his condition.

This is one of the first and deepest injustices people with disabilities face: being seen as too complicated, too rare, too hard to help. But no life is too small or too complex to be treated with



dignity. Benício was not a case. He was a boy — a boy with a family that loved him fiercely, and a quiet strength that left us all in awe.

In 2024, he had a severe pneumonia and was hospitalized for 67 days. He needed a tracheostomy to breathe, and from that point on, his health became even more fragile. In January 2025, he got another pneumonia and passed away two days later.

Before he died, we finally managed to get access to a cannabis-based medication that science strongly supports for his condition. For months, we had asked doctors to consider it, but many insisted on exhausting “traditional” options first. He was only prescribed the treatment at the very end — but even in that short time, we saw small changes. He began to follow our voices with his eyes. He seemed more present. We had hope. And then, it was gone.

We Need a Truly Inclusive Society

Benício's story is not just about a disease. It's about the way our systems fail people who need the most support—and how society often reduces disability to an inconvenience or a problem, instead of recognizing it as a part of human diversity. The problem is how unprepared—and often unwilling—society is to adapt.

In many cultures, disability is still seen through a lens of pity, or worse, invisibility. People avoid the topic. They don't know how to act. They speak in terms that reduce the person to their condition: "a disabled child," "a special needs kid," rather than a child who happens to have a disability. Language matters. It shapes perception. And perception shapes action.

If we want to build a truly inclusive society, we need more than just ramps and accessible bathrooms. We need accessible systems—health care, education, therapies—that actually reach those who need them. We need policies that don't delay effective treatments out of fear or bureaucracy. We need to listen to families, and to the people with disabilities themselves.

Benício's life was short, but it changed ours forever. His story reminds me every day that inclusion is not kindness—it's justice. And justice delayed, as we know, is justice denied.

AFTER YOU READ:

1. Bruna says that "inclusion is not kindness—it's justice." What does she mean? What is the difference between kindness and justice?
2. Read the box on the right. What do you think might be the similarities between the civil rights movement and the disability rights movement?
3. Look at the list of resources on p. 37 and click on the links to learn more about disability justice.

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Justice Delayed Is Justice Denied



Martin Luther King was a leader of the civil rights movement in the United States. He helped organize people to fight back against discrimination. One tactic they used was non-violent civil disobedience.

In 1963 in Birmingham, Alabama, activists decided to have a protest. The city had a new rule that did not allow protesting without a permit. King and others decided to hold a protest anyway. King and 50 other protesters were arrested and put in jail.

Some religious leaders criticized King for leading these protests. They thought he should be more patient and moderate in his efforts. In response, King wrote the famous "Letter from a Birmingham Jail." In the letter, he said he could not be patient because "justice too long delayed is justice denied."

Read more about it here: <https://www.history.com/articles/kings-letter-from-birmingham-jail-50-years-later>.