

A photograph of a person with a physical disability, seen from behind, walking on a dirt path through a field of tall, green grass. The person is wearing a dark brown wrap around their waist and is using a metal cane for support. The background shows a clear blue sky with some light clouds.

ONE BILLION FORGOTTEN

PROTECTING THE HUMAN RIGHTS
OF PERSONS WITH DISABILITIES

ONE BILLION FORGOTTEN



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INTRODUCTION

Across the world, more than one billion people – or 15% of the world’s population – live with disabilities. They face significant barriers to realizing their human rights, including discrimination in education, employment, housing and transport; denial of the right to vote; and being stripped of the right to make decisions about their own lives, including their reproductive choices. Individuals with physical, sensory, intellectual and mental disabilities often face increased violence, yet they remain invisible in their communities. Governments fail to protect their rights, and make access to redress difficult.

Over the past few years, Human Rights Watch has become a pioneer in mainstreaming disability rights within the broader human rights agenda, and is seen by disability rights experts and disability rights organizations as an important partner in global advocacy efforts. In more than 25 countries, our work has addressed a broad range of issues such as violence against women and children with disabilities, access to education and health care, institutionalization, legal capacity, political participation and the impact of armed conflict.

Through our global advocacy, we have pressed for broader ratification and implementation of the groundbreaking Convention on the Rights of Persons with Disabilities and stronger protections for people with disabilities worldwide. Specifically, we have monitored legal reform processes in a number of countries and incorporated disability rights concerns in our advocacy on such issues as violence against children and abusive treatment in health care.

This brochure highlights Human Rights Watch’s growing body of work and advocacy to uphold the rights of people with disabilities around the world.

RECENT IMPACT

Increased pressure for ban on solitary confinement in the AMERICAS: Following our report and joint advocacy, the Inter-American Commission on Human Rights formally recommended that members of the Organization of American States adopt a ban on solitary confinement of persons with mental disabilities.

People with Mental Disabilities No Longer Categorically Excluded from Voting in LIBYA: Human Rights Watch raised concerns about voting restrictions on people with mental disabilities in the 2012 draft electoral law, and this provision was subsequently removed before the law was passed.

Stronger Protections for People with Mental Disabilities in GHANA: After the publication of our 2012 report "Like a Death Sentence," which describes how people with mental disabilities suffer severe abuses in psychiatric institutions and "prayer camps", the Ghanaian government made a commitment to monitor the spiritual healing centers through regular visits, and to prepare the necessary legal regulations to implement the country's new mental health law.

Greater Awareness of HIV and Disability Through Multimedia: Our video about a South African disability rights advocate living with HIV led to a CNN feature program: "Deaf, gay and HIV positive activist battles against stigma", raising significant public awareness of this cross-cutting issue. The Joint UN Program on HIV/AIDS (UNAIDS) screened our video at its executive board meeting and in briefings for its staff in Geneva, increasing understanding among program staff about the need for disability-inclusive HIV programs and policies.

CROATIA Adopts Deinstitutionalization Plan: Following our 2010 report "Once You Enter, You Never Leave," the Croatian government adopted a plan for deinstitutionalization of the more than 9,000 people with intellectual or mental disabilities living in institutions.

RUSSIA Takes Steps Towards Accessibility: Following our 2013 report "Barriers Everywhere", the Moscow Metropolitan Authority committed to making 38 metro stations more accessible for people who are blind or low vision. The Ministry of Labor also adopted an order requiring employers to adapt workplaces to the individual needs of people with disabilities.

COUNTRIES WITH RECENT RESEARCH AND ADVOCACY

Limits to Arbitrary Detention of People with Mental Disabilities in PERU: As a result of HRW joint advocacy with local disability advocates, the government of Peru abolished a law permitting involuntary detention for treatment of people with psychosocial or mental disabilities in circumstances that did not comply with international human rights law.

Gender-Based Violence Programs More Inclusive of Women and Girls with Disabilities in NORTHERN UGANDA: Drawing upon our 2010 report "As If We Weren't Human," international organizations providing services for survivors of sexual and gender-based violence in Uganda developed targeted outreach and training programs for women and girls with disabilities, in partnership with disabled persons' organizations. These organizations are also providing training for health workers, police and lawyers on how to intervene in cases of violence against women with disabilities.

Concrete Steps Toward Inclusion of Children with Disabilities in Schools in NEPAL: Responding to our 2011 report "Futures Stolen," the World Bank and other development partners in Nepal began developing a strategy to integrate children with disabilities in their programs. The Department of Education also began developing a curriculum for children with intellectual disabilities with participation of local disabled persons' organizations.

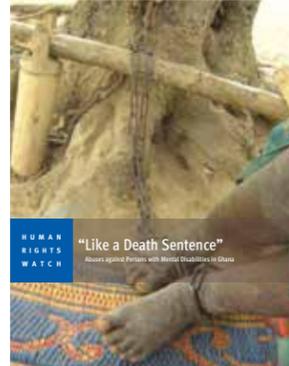


DISABILITY RIGHTS IN INSTITUTIONS AND PLACES OF DETENTION

Under the presumption of mental disability, countless individuals around the world languish in psychiatric institutions for years, some without adequate access to mental health services, personal hygiene, or even water. Conditions in such institutions are rife with mistreatment, including verbal abuse and beatings, forced treatment, lack of medication, and use of restraints and confinement as punishment. Our long-term goal is a systematic shift in the treatment of people with mental disabilities from institutionalization to community integration.

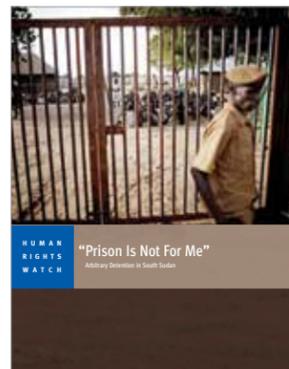
“LIKE A DEATH SENTENCE”: ABUSES AGAINST PERSONS WITH MENTAL DISABILITIES IN GHANA

This report describes how thousands of people with mental disabilities are forced to live in psychiatric institutions and spiritual healing centers, often against their will and with little possibility of challenging their confinement. In psychiatric hospitals, people with mental disabilities face overcrowding and unsanitary conditions. In some of the spiritual healing centers, popularly known as prayer camps, they are often chained to trees, frequently in the baking sun, and forced to fast for weeks as part of a “healing process,” while being denied access to medications.



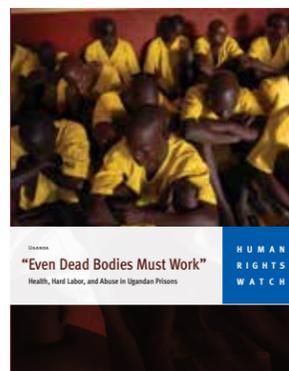
“PRISON IS NOT FOR ME”: ARBITRARY DETENTION IN SOUTH SUDAN

This report documents violations of due process rights, patterns of wrongful deprivation of liberty, and the harsh, unacceptable prison conditions in which detainees live. Conditions for prisoners with mental disabilities are particularly harsh. Human Rights Watch found 90 individuals imprisoned for being said to show evidence of mental disability; very few were accused of a criminal offense. Some of these prisoners are chained day and night while naked and soiled in excrement, unable to access proper health care. They cannot appeal their incarceration and most have no release date.



“EVEN DEAD BODIES MUST WORK”: HEALTH, HARD LABOR, AND ABUSE IN UGANDAN PRISONS

This 80-page report documents routine physical abuse and the failure of the criminal justice system to protect the rights of prisoners. Prisoners at rural prisons, including the elderly, individuals with disabilities, and pregnant women, are frequently caned, or are even stoned, handcuffed to a tree, or burned, when they refuse to perform hard labor. HIV and TB patients may be denied care and sent to farm prisons far from treatment programs.



“ONCE YOU ENTER, YOU NEVER LEAVE”: DEINSTITUTIONALIZATION OF PERSONS WITH INTELLECTUAL OR MENTAL DISABILITIES IN CROATIA

This report documents the plight of the more than 9,000 persons with intellectual or mental disabilities living in institutions in Croatia and the lack of community-based programs for housing and support. Human Rights Watch research found that while more than 4,000 persons with mental disabilities are living in institutional settings in Croatia, the country has places for only seven people in supportive community living programs. The situation is not much better for people with intellectual disabilities: Croatia has facilities for only about 250 people in community living programs, while approximately 5,000 remain in institutions.



Doris Appiah © 2012 Human Rights Watch

DORIS'S STORY

“I used to feel lonely ... ashamed ... [being in the hospital]. ...What I needed was a clinical psychologist to talk to and community-based rehabilitation, but these services are not easy to come by.”

— Doris Appiah, a woman with mental disability, Ghana

Doris lives with bipolar disorder and at 22, she was taken to a “prayer camp,” a type of spiritual healing center, where she lived for five years, tied to the wall with ropes, forced to fast and slept, bathed and defecated in the open. As is typical for prayer camps, the camp was run by a self-described prophet who claimed to receive instructions from God about how to treat individuals like Doris, whom he said were “possessed by demons.” Doris, now 58, overcame the experience of the prayer camp, as well as time spent in deplorable conditions in psychiatric hospitals where she witnessed severe abuse against people with mental disabilities. She completed her studies as a nurse, started a family and is now a human rights advocate, working with community groups to help families and persons with mental disabilities rediscover their lives after institutionalization. Doris helped Human Rights Watch with research and advocacy surrounding the publication of *Like a Death Sentence: Abuses Against Persons with Mental Disabilities in Ghana*.



POLITICAL PARTICIPATION AND ACCESS TO JUSTICE

Lack of access to civil, political and economic rights for people with disabilities – including the right to a fair hearing, to vote, marry, seek employment, and access health services – is commonplace worldwide. As Human Rights Watch’s country-specific research has shown over recent years, deprivation of legal capacity – or the right to make decisions about one’s own life – profoundly impacts people with disabilities. Indeed in many countries, national laws treat persons with disabilities as unequal citizens, sometimes allowing them fewer rights than children. This body of work underscores that no citizen should be denied their civil and political rights on the basis of a disability.

Using sign language, Monica, a deafblind woman, expresses her opinion on her right to political participation. She is a member of SENSE International Peru, an NGO working with deafblind people and their families.
© 2011 Human Rights Watch

BARRIERS EVERYWHERE: LACK OF ACCESSIBILITY FOR PEOPLE WITH DISABILITIES IN RUSSIA

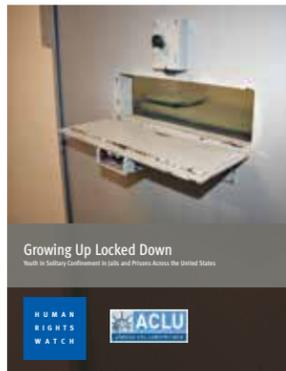
This report documents everyday hurdles people with disabilities in Russia meet when going to government offices, shops, healthcare centers, places of employment, and accessing public transportation. Those with physical disabilities who use wheelchairs or crutches may be confined to their homes because elevators are broken or nonexistent. Many with disabilities receive substandard healthcare because of a lack of specialists in their communities and health workers' unwillingness to speak directly with them. People who are blind or have low vision struggle with the lack of tactile on public transportation.



SEPTEMBER 2013

GROWING UP LOCKED DOWN: YOUTH IN SOLITARY CONFINEMENT IN JAILS AND PRISONS ACROSS THE UNITED STATES

The report is based on research in both US jails and prisons in five states -- Colorado, Florida, Michigan, New York, and Pennsylvania -- and correspondence with young people in 14 others. This joint American Civil Liberties Union-Human Rights Watch report document that isolation of solitary confinement causes anguish, provokes serious mental and physical health problems, and works against the rehabilitation of teenagers.



OCTOBER 2012

"I WANT TO BE A CITIZEN JUST LIKE ANY OTHER:" BARRIERS TO POLITICAL PARTICIPATION FOR PEOPLE WITH DISABILITIES IN PERU

This report documents the legacy of a policy, changed only in October 2011, that arbitrarily denied people with sensory, intellectual, and psychosocial disabilities their right to vote, considering them legally incompetent to exercise such a decision. Human Rights Watch also examined the barriers that people with disabilities face when exercising their political rights, including the difficulty of getting identity documents essential for voting, and the absence of support mechanisms to help people with disabilities make voting decisions.



MAY 2012

DEPORTATION BY DEFAULT: MENTAL DISABILITY, UNFAIR HEARINGS, AND INDEFINITE DETENTION IN THE US IMMIGRATION SYSTEM

This report investigates how immigrants with mental disabilities are often unjustifiably detained for years on end, sometimes with no legal limits. The report documents case after case in which people with mental disabilities were prevented from making claims against deportation -- including claims of US citizenship -- because they were unable to represent themselves. Some of the people interviewed for the report did not know their own names, were delusional, could not tell time, or did not know that deportation meant removal from the United States.



JULY 2010



A national identity card, shown here, is required in Peru for voting as well as for financial matters, such as opening a bank account. © 2012 Human Rights Watch

Maria Alejandra's Story

When people are "interdicted," they cannot vote. I have the right to vote. I have the right to elect my candidate. I have the right to inherit. I have the right to study, to health, and to work. I am not incompetent, but [interdiction] would declare me to be.

— Maria Alejandra Villanueva, a young woman with Down Syndrome, Peru

Maria Alejandra, 29, is a leader of the Peruvian Down Syndrome Association. At age 18, she received her first national identity card, required for voting, and voted in subsequent elections. Things changed, however, in 2010 when Maria Alejandra went to renew her identity card at the National Registry for Identification and Civil Status (RENIEC). Maria Alejandra was told that she could not vote because she has an intellectual disability and that, instead, she should be "interdicted," a legal process by which a judge declares a person incompetent to take care of their self and denies the person their right to vote. Maria Alejandra shared her experience about being barred from the voter registry at the UN Conference of States Parties to the Convention on the Rights of Persons with Disabilities in September 2011, and was subsequently featured in a number of media articles in Peru. One month later, following pressure from self-advocates, disabled persons' organizations, civil society groups, and the public ombudsman's office, the government reversed a longstanding policy denying the right to political participation and other civil rights to people with mental and intellectual disabilities.

Five children with intellectual disabilities playing on the classroom floor of a resource class for children with intellectual disabilities at Mahendranagar Secondary School in the far western region of Nepal.
© 2011 Shantha Rau Barriga/Human Rights Watch

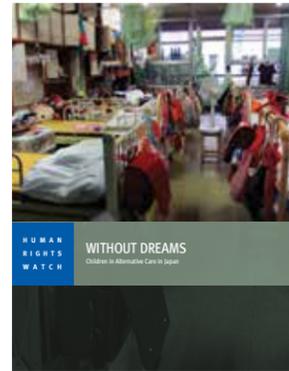
CHILDREN WITH DISABILITIES

There are 120 to 150 million children with disabilities under the age of 18 worldwide. Human Rights Watch has found that children with disabilities are denied access to school, subjected to corporal punishment and other forms of physical violence, and face segregation in schools, institutions and places of detention. In bringing attention to these abuses, our goal is to ensure that children with disabilities are no longer excluded and abused, and instead enjoy the same rights as all other children.



WITHOUT DREAMS: CHILDREN IN ALTERNATIVE CARE IN JAPAN

Some 34,075 children live in child care institutions in Japan and these children will on average spend 5 years living in institutional settings. Children with disabilities are over-represented in this statistic. The report examines the alternative care system’s organization and processes, problems found in the institutionalization of children and infants, and abuses that take place. The report also considers the difficulties many children experience when they leave alternative care, and outlines problems with foster care.



MAY 2014

“AS LONG AS THEY LET US STAY IN CLASS”: BARRIERS TO EDUCATION FOR PERSONS WITH DISABILITIES IN CHINA

This report documents the struggles of children and young people with disabilities in China to be educated in mainstream schools in their communities. Currently, children with disabilities are excluded from mainstream schools unless they can demonstrate the “ability to adapt” to the schools’ physical and learning environment. The report details the ways schools deny these students admission, pressure them to leave, or fail to provide appropriate classroom accommodations to help them overcome barriers related to their disabilities.



JULY 2013

FUTURES STOLEN: BARRIERS TO EDUCATION FOR CHILDREN WITH DISABILITIES IN NEPAL

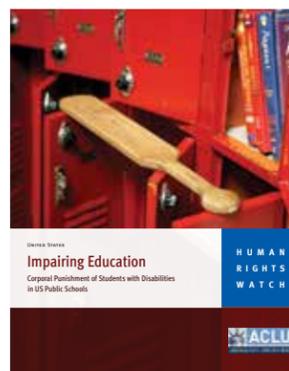
This report documents the hurdles that children with disabilities face in obtaining a quality education in Nepal. Some children with disabilities experience abuse and neglect at home and in their communities, making it harder for them to gain access to schooling. These barriers result in low attendance and high dropout rates for children with disabilities compared with their non-disabled peers.



AUGUST 2011

IMPAIRING EDUCATION: CORPORAL PUNISHMENT OF STUDENTS WITH DISABILITIES IN US PUBLIC SCHOOLS

In this report, the American Civil Liberties Union and Human Rights Watch found that students with disabilities made up 18.8 percent of students who suffered corporal punishment at school during the 2006-2007 school year, although they constituted just 13.7 percent of the total nationwide student population. At least 41,972 students with disabilities were subjected to corporal punishment in US schools during that year. These numbers likely undercount the actual rate of physical discipline, since not all instances are reported or recorded.



AUGUST 2009



Amman and his mother sitting in front of their home, next to a wooden tricycle.
© 2011 Shantha Rau Barriga/Human Rights Watch

Amman’s Story

“I stand him at the gate of the school and he enters by crawling.”

- Lakshmi, mother to Amman, a boy with difficulties in motor skills and speech, Nepal

Amman, a 16-year-old boy with a physical disability limiting his movement and speech, started attending school two years before in his village in far western Nepal. He was in Class 2. His classmates were between 7 and 10 years old. His 11-year-old brother attended the same school but studied in Class 4. Amman uses a tricycle, which was pushed by his mother or other children in the community, to get to school. Because the school entrance had two steep steps and no ramps, Amman had to crawl to his classroom.

His mother, Lakshmi, told Human Rights Watch, “Amman sits [alone] on a smaller chair in the corner. He sometimes drools, so the other children don’t feel easy about sitting near him.”

Amman has to refrain from using the toilet while in school from 10 a.m. to 4 p.m. When he needs to use the toilet during the day, another child has to run home to fetch his mother to assist him. The teachers say that if he has stomach problems, his mother should not bother bringing him to school.



WOMEN AND DISABILITIES

Women with disabilities experience multiple discrimination – as a result of their disability and gender – and face a heightened risk of physical and sexual violence. Many factors contribute to this risk, including limitations in physical mobility, communication barriers, isolation, and common myths that persons with disabilities are weak or asexual. In many countries, an alarming number of women with disabilities continue to be denied reproductive and sexual rights through the practice of forced sterilization. Our goal is to bring an end to violence and discrimination against women with disabilities worldwide.

Few women and girls with physical disabilities have functioning mobility devices that can help them to access basic services such as health centers, police stations or schools. This 35-year old woman has seven children. She uses a hand-crank bicycle to move around her village. But she says she still feels vulnerable to sexual violence and HIV.

© 2010 Martina Bacigalupo for Human Rights Watch

“AS IF WE WEREN’T HUMAN”: DISCRIMINATION AND VIOLENCE AGAINST WOMEN WITH DISABILITIES IN NORTHERN UGANDA

This report describes frequent abuse and discrimination by strangers, neighbors, and even family members against women and girls with disabilities in the north. Women interviewed for the report said they were not able to get basic provisions such as food, clothing, and shelter in camps for displaced persons or in their own communities. The research was conducted in six districts of northern Uganda – a region recently emerging from over two decades of brutal conflict between the rebel Lord’s Resistance Army and the government.



AUGUST 2010

ILLUSIONS OF CARE: LACK OF ACCOUNTABILITY FOR REPRODUCTIVE RIGHTS IN ARGENTINA

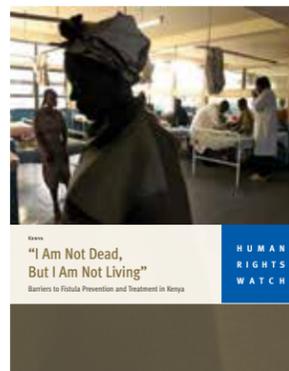
This report documents the many obstacles women and girls face in getting the reproductive health care services to which they are entitled, such as contraception, voluntary sterilization procedures, and abortion after rape. The report demonstrates how obstacles to care can be even harder to overcome for women and girls with disabilities, who must also at times deal with prejudicial treatment from health care providers. The most common barriers to care include lack of physical accessibility, long delays in providing services, unnecessary referrals to other clinics, demands for spousal permission contrary to law, financial barriers, and in some cases outright denial of care.



AUGUST 2010

“I AM NOT DEAD, BUT I AM NOT LIVING”: BARRIERS TO FISTULA PREVENTION AND TREATMENT IN KENYA

This report describes the devastating circumstances women with obstetric fistula in Kenya face, and the wide gap between government’s policies to address reproductive health and the reality of women’s daily lives. Obstetric fistula is a preventable childbirth injury that can lead to long-term disability, and often triggers stigma and the breakdown of family, work, and community life. This report documents health system failures in five areas: education and information on reproductive and maternal health; school-based sex education; access to emergency obstetric care, including referral and transport systems; affordable maternity care and fistula repair; and health system accountability. It also documents stigma and violence many women with fistula face.



JULY 2010

Many Ugandans rely on makeshift mobility devices to get around; this one is at a camp for internally displaced persons in Omee. Some women with physical disabilities who left the camps said that they now have to crawl long distances to health clinics or pharmacies.
© 2010 Martina Bacigalupo for Human Rights Watch



IRENE’S STORY

“One night, when I was sleeping alone, a man who was drunk entered my home and started raping me. My husband was not around. He had gone to look for food. No one came to rescue me, and the man raped me and beat me. I know the man. He lives in the neighborhood. The man was arrested and was held for only one day.”

-Irene, a woman with communicative and physical disabilities, northern Uganda

Irene is a woman with communicative and physical disabilities who communicates with her husband, who has a physical disability, through a combination of a few words, facial expressions and hand gestures. Her husband explained to Human Rights Watch, “I can’t stay away from home. I heard there was food distribution at another camp. ... I went there, but that place was far, and I stayed there for a night. [My] neighbor came back [before me] and raped my wife.” In a follow-up interview with Irene alone, she told Human Rights Watch that her husband had also beaten her in the past. As a result of severely limited ability to move and communicate, Irene has little recourse and almost no ability to report the assaults to others.

SELECT MULTIMEDIA & ADVOCACY



HIV AND DISABILITY:

As part of Human Rights Watch’s advocacy on greater inclusivity of individuals with disabilities in HIV policy and prevention efforts worldwide, we published an advocacy brochure—including an easy-to-read version—and distributed the brochures at the International AIDS Conference in Washington, DC. We also presented on HIV and disability at two panels, distributed multimedia materials on this issue to hundreds of HIV advocacy organizations, and screened a video we produced about a South African disability rights advocate living with HIV. This work led to the CNN feature program: *“Deaf, Gay and HIV Positive Activist Battles Against Stigma.”*

We also produced an audio podcast featuring *HIV activist Winstone Zulu and disability advocate Myroslava Tataryn*, which led to an opinion piece on HIV and disability in the *New York Times*. We are continuing our advocacy on this issue, including pressing for the next international AIDS conference in 2014 to have a greater focus on disability and HIV.



DISABILITY RIGHTS IN RUSSIA:

Human Rights Watch created a multimedia piece, *Breaking Barriers: Disability Rights Movement in Russia*, featuring photos from Platon, to bring attention to the efforts of disability rights advocates in Russia. We also drafted an op-ed that appeared in a major Russian newspaper and a dozen online media outlets.

Top photo: John Meletse is a deaf, gay, and HIV-Positive South African man. © 2012 Human Rights Watch
Left photo: © 2012 Human Rights Watch

AT THE CORE

Human Rights Watch’s approach to our disability rights work has centered on working in partnership with disabled persons’ organizations and persons with disabilities. This approach recognizes the expertise within the disability community and honors the principle of participation, enshrined in the Convention on the Rights of Persons with Disabilities.

Our disability rights work references a number of key principles and standards set out in the Convention on the Rights of Persons with Disabilities, including:

- Principle of “reasonable accommodation”
- Non-discrimination
- Accessibility
- Situations of risk and humanitarian emergency
- Equal recognition before the law
- Access to justice
- Freedom from violence and exploitation
- Protecting the physical and mental integrity of the person
- Respect for home and the family
- Education
- Health
- Habilitation and rehabilitation
- Adequate standard of living and social protection
- Political participation

Human Rights Watch has broken new ground with our research and advocacy on disability rights under the focus of a human rights lens.

We hope to continue to advance our disability rights work, strengthen our collaboration with disabled persons' organizations in raising public awareness of abuses, and conduct strategic advocacy at the highest levels to effect change in the lives of persons with disabilities on the ground. We look forward to partnering with you and other allies in this effort.



FOR MORE INFORMATION,
VISIT: WWW.HRW.ORG/DISABILITY

People with physical disabilities living in remote places, like Filda, a woman in Uganda have difficulty reaching HIV services, as well as entering them when they arrive.

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