



“They Stay until They Die”

**A Lifetime of Isolation and Neglect in Institutions for People
with Disabilities in Brazil**

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II. Treatment and Conditions in Institutions

Human Rights Watch visited 19 institutions in Brazil in four states, including 11 institutions for adults with disabilities and 8 institutions for children, including 5 exclusively for children with disabilities.¹⁸ All adult institutions also had children, and some of the specialized institutions for children with disabilities also housed adults.

Institutions ranged in size from 20 to 110 persons. Most institutions had approximately 30 to 50 people. In several institutions, Human Rights Watch documented abuses including ill-treatment, neglect, the use of restraints to control or punish residents, sedation, as well as inhumane and degrading conditions. Conditions and treatment were particularly abusive in the institutions we visited that had large numbers of people with high support requirements.

Many institution managers claimed that they did not have adequate staff to provide individualized attention to residents. For children, research has shown that the absence of a one-to-one relationship with a primary caregiver is a major cause of harm to a child's development and attachment disorders. Most children with disabilities in institutions did not go to school. For those who did receive education, it was not meaningful to develop academic or life skills and took place primarily in segregated settings.

Most of the staff Human Rights Watch spoke with in institutions were highly committed and motivated to support persons with disabilities. They frequently emphasized that they were doing the best they could with the little resources they had. However, even well-intentioned staff often engage in unacceptable practices because they lack information, training, as well as resources, such as additional personnel, to help them care for large numbers of people, especially those requiring more intense forms of support.

People with disabilities have the right, on an equal basis with others, to be free of inhuman and degrading treatment as well as not to be subjected to forced medical treatment or restraints. Children enjoy this same right, as well as the right to education, play, and leisure.

¹⁸ Human Rights Watch also visited five inclusive residences.



Staff in an institution in Rio de Janeiro bind the hands of children with disabilities to prevent them from biting their fingers or scratching themselves instead of implementing other methods, such as providing one-to-one personal support to prevent children from harming themselves. Due to the lack of sufficient staff, “We are unable to provide one to one personal attention all the time,” one staff member said.

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Use of Restraints and Isolation

In eight of the 19 institutions that Human Rights Watch visited which held more than 50 residents, staff restrained adults and children in various ways. Staff restrained residents to bed rails with pieces of cloth bound around their waists or their wrists. In two institutions, Human Rights Watch saw how staff tightly bound socks or cloth around children’s hands to prevent them from putting their hands in their mouths or scratching themselves.

In one institution, staff told Human Rights Watch that “at times we use straitjackets and placed people in an isolation room for them to calm down.” A nurse said, “Sometimes



A man with disabilities looks out through the bars of a psychiatric ward in an institution in Rio de Janeiro. Persons locked in this section of the institution never left their rooms, according to staff. © 2016 Human Rights Watch

we ... restrain them with sheets, or we use straitjackets for about 30 minutes while waiting for medication to take effect.”¹⁹

Staff at some facilities stated that they restrained individuals in order for them not to hurt themselves.²⁰ Staff in institutions Human Rights Watch visited in Brazil appear to rely on restraints because there are not enough personnel to allow them to give individuals the attention and support required to help them manage behavior that could be harmful.²¹ Although the government has issued technical guidelines for staffing levels in institutions for children, they are non-binding. There are no guidelines for staffing for adult institutions (*abrigos-institucionais*).²² In one institution in

Rio de Janeiro only four staff members at a time provided direct support to 51 adult residents, all with high support needs.

¹⁹ Human Rights Watch interview with staff members in an institution, November 7, 2016 (location withheld for security reasons).

²⁰ Human Rights Watch interview with staff members in institutions (locations and dates withheld for security reasons).

²¹ For children’s institutions, technical guidelines establish minimum staffing requirements, but are not binding. For institutions with children with disabilities the guidelines call for increased staff. “Technical Guidelines: Reception Services for Children and Adolescents,” pp. 68-69. Inclusive Residences also have staffing guidelines. “Technical Guidelines on the Institutional Reception Service for Youth and Adults with Disabilities in Inclusive Residences. Questions and answers,” November 2014, p. 44.

²² Human Rights Watch interviews with staff at an institution, Rio de Janeiro, November 7, 2016; staff at an institution, near the Federal District, November 18, 2016; and at an institution, Bahia, April 5, 2017.

Restraint is never acceptable as a means of punishment or behavior control and it could amount to torture or ill-treatment. The special rapporteur on torture has stated that “any restraint on persons with disabilities for even a short period of time may constitute torture and ill-treatment.”²³

The World Health Organization (WHO) has found that aggressiveness and unwanted behavior can often arise when individuals are constrained by the inherently rigid nature of the institution that does not give adequate attention to an individual’s will and requirements.²⁴ The WHO is designing programs to train staff to prevent situations that can escalate into aggressiveness, violence, and behavior that could result in self-harm. One key element is creating an institutional environment that recognizes individual needs and requirements and provides services in a timely and dignified manner. Other alternatives are designing individualized plans to understand and recognize triggers, early warnings, and tense situations.²⁵ The Brazilian government should move quickly to implement these types of measures while working towards deinstitutionalization.

Confinement to Beds and Rooms

Human Rights Watch visited eight institutions where residents remained in their beds or rooms continuously or for extended periods of time, including for meals. In five adult institutions, metal beds had tall metal bars to confine some residents with intellectual disabilities.

Many people whom staff considered “severely disabled” (*muito comprometidos*), especially those who had multiple disabilities and could not move by themselves, remained almost continuously in their beds, lying down, doing nothing. At the time of Human Rights Watch’s visit to one institution, 32 residents, both children and adults, were all lying in their beds or cribs.²⁶ In one institution, a staff member confirmed that residents

²³ Report of the United Nations Special Rapporteur on Torture, A/HRC/22/53, Human Rights Council, 22nd session, February 1, 2013.

²⁴ World Health Organization (WHO), “Strategies to end the use of seclusion restraint and other coercive practices,” WHO QualityRights Guidance and Training Tools, WHO/MSD/MHP/17.9, http://who.int/mental_health/policy/quality_rights/guidance_training_tools/en/ (accessed January 31, 2018).

²⁵ Ibid.

²⁶ Human Rights Watch visit to an institution, Rio de Janeiro, November 8, 2016.



An overcrowded room with 40 children with disabilities in an institution in Bahia. Many institution managers reported that they had insufficient staff to care for the large number of residents. © 2017 Human Rights Watch

with high support needs lay down almost continuously, being brought out of bed and placed in a wheelchair only for short periods.²⁷ In one of the institutions Human Rights Watch visited in Rio de Janeiro, dozens of people with so-called “severe” disabilities were separated on the upper floor of the building. Up to eight people lived in small rooms, some of them restrained to metal bars of the bed by a cloth around their waists. A nurse in this institution said that people there “never leave the room.”²⁸

A specialized institution for persons with cerebral palsy in São Paulo had a ward for persons with high support requirements, where people lay in bed almost

continuously, connected to oxygen tanks in the wall through tubes. According to one staff member, residents sat in wheelchairs for some hours during the mornings but had limited other activity. They never left the institution.²⁹ In Salvador, in one institution for 87 people, some people lay in bed constantly without stimulation or activity; another institution for 109 children had one room with children who similarly lay in beds continuously.³⁰

In some institutions, most residents wore diapers and did not even get out of bed to use the toilet. A nurse in one institution told us, “All people who live in this ward use

²⁷ Human Rights Watch interview with institution staff, São Paulo, November 15, 2016.

²⁸ Human Rights Watch interview with institution staff, Rio de Janeiro, November 7, 2016.

²⁹ Human Rights Watch interview with institution staff, São Paulo institution, November 15, 2016.

³⁰ Human Rights Watch visits to institutions, São Paulo April 5, 2017; and Salvador, Bahia, April 5, 2017.

diapers.”³¹ The parent of one resident told Human Rights Watch that she believed some residents, including her son, could use toilets if proper support was provided.³²

Human Rights Watch observed that, except for wheelchairs in some cases, there were no other mobility devices like hoists or other instruments of any kind in any of the institutions visited to enable persons with physical disabilities to get out of their beds, much less to go out of the institution. Residents were not able to get up and walk without such assistance were completely dependent on the staff.

For example, Leonardo Barcellos, a 25-year-old with muscular dystrophy, was placed in an institution for people with high support needs when he was 15. He lived in one large room, along with 24 other men and women. He told Human Rights Watch that he spends large parts of his day in bed due to the lack of personnel to move him:

I am placed in the wheelchair in the morning, but then I have to be put back into my bed because I’m heavy, and there is no one to put me back again in the evenings. I miss my home and would want to live with my mother, but I understand she is getting older and wouldn’t be able to support me physically.³³

In one institution in Salvador, an 18-year-old man with a progressive disability, which gradually compromised the muscles in his legs, had difficulty getting out of the room he shared with one other person. He did not have a wheelchair and moving on his own was extremely painful. Although the institution was located just 200 meters from the sea, he was unable to go to the beach and told Human Rights Watch that his dream was to “see the sea.”³⁴

³¹ Human Rights Watch interview with an institution staff member, Rio de Janeiro, November 8, 2016.

³² Human Rights Watch visit to an institution, Rio de Janeiro, November 8, 2016.

³³ Human Rights Watch interview with Leonardo Barcellos, Rio de Janeiro, March 28, 2017.

³⁴ Human Rights Watch interview with Alvaro [not his real name] in an institution, Salvador, November 6, 2017.



A young man with a physical disability sitting in his room in an institution in Bahia, located approximately 2000 km from the Atlantic Ocean. “My dream is to see the sea, but I have no wheelchair to go and see it,” he said. © 2017 Human Rights Watch

Inhumane and Degrading Conditions

Most of the large institutions had an impersonal and hospital-like or detention center-like environment. In some institutions, doors and windows had bars on them, giving them the appearance of detention centers. Conditions in institutions in Brazil that Human Rights Watch visited were often dehumanizing. In some cases, large numbers of unrelated adults or children were kept in rooms together, sometimes in severely crowded rooms of up to 32 people. In addition to being confined to the institution, many people remained in their rooms or beds for most or all of the day either because they were restrained to the beds or because staff did not provide support for people to leave their beds.



A group of persons with disabilities in a yard in an institution in Rio de Janeiro. Residents are taken outside for a few hours during the day but spend most of the time confined to their beds.

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A bathroom in an institution in the outskirts of Brasília (Distrito Federal). Many institutions for persons with disabilities in Brazil do not ensure residents' privacy. © 2017 Human Rights Watch

Residents overwhelmingly had no privacy and had few or no personal items. In some cases, they even had to share clothes—and in one facility, even toothbrushes—with others. In some adult institutions staff did not assist residents to get dressed, leaving them unclothed from the waist down, wearing only diapers. Several institutions advertised tours for the public and solicited donations online relying on images of persons with disabilities as needy, vulnerable, and in need of care, rather than as autonomous individuals. In many of the institutions visited by Human Rights Watch, the problems described below created an inhumane and degrading living environment for residents.

Overcrowding and Lack of Privacy

Serious overcrowding was a problem in a number of institutions visited by Human Rights Watch. For example, in a Salvador institution for 109 children, one room held about 28 beds in four rows placed side by side with very little room to move between the rows and with no separation between beds to provide basic privacy. In one institution for adults 32 people lived in one room, again with beds placed directly next to each other. Some institutions had large wards with only small walls that separated groups of six to seven people. At least one staff member was constantly present. One of these overcrowded institutions had a bathroom where there were no doors or other means of privacy separating the toilets.

In five institutions visited, people slept in rooms with nothing but a bed (or multiple beds) or a mattress on a concrete platform.³⁵ In one case people lay on mattresses on floors. The director of that facility claimed that the beds were being painted. Some slept on bare mattresses with no bottom sheet, but only a sheet to cover them. There was no other furniture that might be found in a bedroom, such as a bedside table, shelves for personal belongings, or dressers or bureaus for clothing.

In some institutions visited by Human Rights Watch, residents did not have any personal items.³⁶ In one institution a nurse told us, “We don’t have separate toothbrushes for each of them. They share.”³⁷ In some institutions staff stated that people living there were required to share clothes.³⁸



Young man lying down in a mattress in an empty room in an institution in Rio de Janeiro. Most adults and children with disabilities in institutions have few, if any, personal items. In many institutions beds consist of concrete platforms with bare mattresses covered only with a sheet. © 2017 Human Rights Watch

International human rights law requires that all persons with disabilities be treated with dignity. Respecting the inherent dignity of persons with disability entails acknowledging them as persons on an equal basis with others and not as objects of treatment and

³⁵ Human Rights Watch visits to one institution in Rio de Janeiro, two institutions in Bahia, and three institutions near the Federal District, April 5, 2017.

³⁶ Human Rights Watch interview with an institution staff nurse, Rio de Janeiro, November 7, 2016.

³⁷ Human Rights Watch interview with an institution staff nurse, Rio de Janeiro, November 7, 2016.

³⁸ Human Rights Watch interview with [name withheld] in [place withheld], November 2016.

care.³⁹ International law also establishes the right to privacy, including for people with disabilities on an equal basis with others. This applies regardless of their place of residence or living arrangements.⁴⁰

Failure to Assist Adults with Dressing and Lack of Privacy When Changing Diapers

Human Rights Watch visited seven institutions in all municipalities where staff did not support adults deemed to have “severe disabilities” to dress fully. As a result, these residents only wore clothes on the upper halves of their bodies, wearing nothing below the waist except a diaper. This is done for the convenience of staff members when changing peoples’ diapers. In addition, because beds are placed directly next to each other without any separation, staff changed residents’ diapers in full view of other adults.

Staff in one institution said that diapers were in short supply with only two diapers per adult or child per day. As a result, some residents had to remain in their own waste for long periods of time. Female residents in the same institution are not provided with sanitary pads for menstruation, “so we use diapers instead,” according to one nurse.⁴¹

Human Rights Watch considers the failure to fully dress residents and the failure to ensure privacy when changing adult diapers to potentially



A man with a disability in an institution in Bahia wearing nothing but a diaper from the waist down. Staff in some institutions in Brazil do not fully dress adults with disabilities, in disregard for their dignity.

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³⁹ United Nations Convention on the Rights of Persons with Disabilities (CRPD), adopted December 13, 2006, G.A. Res. 61/106, Annex I, UN GAOR, 61st Sess., Supp. (No. 49) at 65, UN Doc. A/61/49 (2006), entered into force May 3, 2008, arts. 1, 3, and 5.

⁴⁰ CRPD, art. 22.

⁴¹ Human Rights Watch interview with an institution nurse, Rio de Janeiro, November 7, 2016.

rise to the level of degrading treatment. The failure to provide women with sanitary pads for menstruation is dehumanizing.

Neglect and Lack of Meaningful Activities in Institutions

In all institutions that Human Rights Watch visited, children and adults with disabilities lacked sufficient personal attention and meaningful activities. Overwhelmingly, institution staff stated that they did not provide individual attention to residents, due to the large number of residents and lack of sufficient personnel to work directly with them. Staff said that they focused almost exclusively on basic care, such as feeding, toileting, and managing sleep routines, with time only for occasional leisure activities. Human Rights Watch's observations in institutions confirmed few staff caring for large numbers of residents at one time, with little time except to meet residents' basic needs. As noted above, lack of sufficient personal attention and consideration of individual needs can contribute to aggression, self-harm, and other undesirable behaviors.

A staff member in one of the institutions said that children there are deprived of personal contact. She said, "We cannot give them that. They need to be held, but we don't have time to hold them." She continued:

The main [issue] is individualized care.... In many institutions, they only provide food and a bed. Kids don't spend time playing. Caregivers are only concerned to give food and put them to sleep. There is no affection, no play. Life is not only eating and sleeping.⁴²

In many institutions which Human Rights Watch visited, some or most residents, both adults and children, were just staring at whatever was in front of them without engaging in any activity. This was true in all 10 institutions for adults Human Rights Watch visited.

In one institution for example, which Human Rights Watch visited at noon, all 32 residents were sitting or lying down in a large, dark room doing nothing. Staff explained that they turned off the lights regularly because of the heat.

⁴² Human Rights Watch interview with institution director, Rio de Janeiro, November 8, 2016.



A young man restrained to his bed in an institution for 32 people with disabilities in Rio de Janeiro. Staff in some institutions for people with disabilities in Brazil physically restrained adults to bed rails with pieces of cloth bound around their waists or wrists. © 2016 Human Rights Watch

At the time of Human Rights Watch's visit to a special institution for children with disabilities in Rio de Janeiro in the middle of the day, all 12 children living there were lying in their cribs without anything to engage them.⁴³ In five institutions in Rio de Janeiro and São Paulo, staff placed children in front of the television to watch whatever program was on.⁴⁴ In one institution visited, dozens of children under the age of 10 were placed in front of a television for the entire time of Human Rights Watch's four-hour visit.⁴⁵ Some activities were organized within the institutions for children and adults, including by bringing in outside groups to provide entertainment. For example, a group of volunteers dressed as clowns makes periodic visits to the institutions to entertain residents.

⁴³ Human Rights Watch visit to an institution, Rio de Janeiro, November 8, 2016.

⁴⁴ Human Rights Watch visits to one institution in São Paulo and three institutions in Rio de Janeiro, November 14, 2016.

⁴⁵ Human Rights Watch visit to an institution in Rio de Janeiro, November 8, 2016.

Staff in some residences said that they occasionally organize trips outside of the institution to the beach, the movies, and other activities. However, in some institutions these trips are rare and in others nonexistent.

One teenager with a physical disability living in a special institution for children with disabilities said:

The institution is stressful because it is noisy and boring. Often I have nothing to do when I'm not at school. I don't have privacy or a space for myself. Special day trips are only organized during weekends, but the staff member in charge of taking us out had an accident and injured herself, so we are not currently going out at all."⁴⁶

The Convention on the Rights of the Child (CRC) establishes the right of children to engage in play and recreational activities appropriate to their age.⁴⁷ The CRPD establishes the right of children with disabilities to have equal access with other children to participation in play, recreation and leisure, and sporting activities.⁴⁸

Institution Fundraising Based on Negative Stereotypes of People with Disabilities

Many private institutions for persons with disabilities, including those visited by Human Rights Watch, promote tours and encourage donations. They advertise tours on their websites and through social media, such as Facebook.⁴⁹ One institution advertised tours for the public of up to five people twice a day; groups of over five people could be arranged on Saturday. Visitors can take photos and videos with authorization. The website tells

⁴⁶ Human Rights Watch interview with Cecilia [not her real name], Rio de Janeiro, March 27, 2017.

⁴⁷ Convention on the Rights of the Child (CRC), adopted November 20, 1989, G.A. Res. 44/25, annex, 44 UN GAOR Supp. (No.49) at 167, UN Doc. A/44/49 (1989), entered into force September 2, 1990, art. 31.1.

⁴⁸ CRPD, art. 30.5.

⁴⁹ Human Rights Watch interview with institution administrator, Rio de Janeiro, November 15, 2016. Acao Crista Vicente Moretti Facebook page: <https://pt-br.facebook.com/AcaoCristaVicenteMoretti/>; La Maria de Lourdes Facebook page: <https://pt-br.facebook.com/larmariadelourdesrj/>; Lar da Redenção Facebook page: <https://www.facebook.com/LAR-DA-Reden%C3%A7%C3%A3o-660323963998341/>; Casa da Criança Betinho Facebook page: <http://www.casadacriancabetinho.com.br/>; Vila Pequeninino Jesus Facebook page: https://www.facebook.com/pg/vilapequeninojesus/reviews/?ref=page_internal. Abrigo Betel Facebook page: <https://www.facebook.com/abrigobetel/?f=484170998408596>.

visitors to take care when speaking with institution residents because they are “sensitive persons and that sometimes they fantasize.”⁵⁰

Human Rights Watch also examined the websites of eight other institutions which had similar videos and appeals. The institution websites viewed by Human Rights Watch foster a negative image of persons with disabilities and perpetuate and reproduce stigmas by portraying institution residents as vulnerable and needy rather than as autonomous persons whose individual choices and inherent dignity must be respected.

The CRPD obligates governments to combat stereotypes, prejudice, and harmful practices relating to persons with disabilities, including by encouraging all organs of the media, as well as social media, to portray persons with disabilities in a manner consistent with the purpose of the CRPD.⁵¹ The CRPD committee has stressed, in numerous concluding observations regarding states compliance with the convention, that charitable campaigns that stereotype persons with disabilities as objects of charity are incompatible with the objective and purpose of the CRPD.⁵²

Involuntary and Potentially Inappropriate Use of Psychoactive Medications

Although our research did not focus on inappropriate medication of people with disabilities living in institutions, we encountered several examples of residents whom the staff said were drugged to control their behavior. Staff at several institutions confirmed that they put residents on psychoactive medications without seeking their consent. The use of medications as chemical restraints to control residents’ behavior—for staff convenience or as punishment—violates international human rights standards.

⁵⁰ Abrigo Ceilândia Esperança webpage, <http://abrigodeceilandia.blogspot.mx/>.

⁵¹ CRPD art. 4.1 (e), in conjunction with art. 5.

⁵² United Nations Committee on the Rights of Persons With Disabilities, Concluding Observations on Peru, CRPD/C/PER/CO/1, May 9, 2012, paras. 18 and 19; Mexico, CRPD/C/MEX/CO/1, October 27, 2014, paras. 17 and 18; Colombia CRPD/C/COL/CO/1, September 30, 2016, paras. 20 and 21; Guatemala, CRPD/C/GTM/CO/1, September 30, 2016, paras. 25 and 26; Uruguay, CRPD/C/URY/CO, August 31, 2016, paras. 19 and 20; and Chile, CRPD/C/CHL/CO/1, April 13, 2016, paras. 17 and 18.

In March 2017, Human Rights Watch researchers encountered a 19-year-old man with an intellectual disability lying motionless on a mattress in the middle of the day in a noisy institution. The institution’s director explained that staff had given him sedatives because he had bitten people.⁵³ She said that 12 of the 24 residents in the institution were on Risperdone, prescribed by a doctor, an antipsychotic medication that was developed to treat schizophrenia. Not all of the patients had schizophrenia. The facility had not sought informed consent from the residents for the use of the medications.⁵⁴

Staff at several other institutions said that they use psychoactive medications to control resident behavior as well. A nurse in an adult institution stated, “If the residents misbehave they are given medication.” Another staff member in the same institution said, “In order to control them, we sedate them; some of them are given sleeping pills.”⁵⁵ In another adult institution, Human Rights Watch visited a ward with eight people, where medical staff said they gave medication to residents to “make them stable, to control crises, or to sedate them.” One staff member said, “If we don’t medicate them they become aggressive.”⁵⁶

A rigid institutional routine, confinement, the lack of meaningful activities, and frequent lack of recognition of the individual will and preferences of residents in institutions can trigger aggressive behavior.⁵⁷

While staff at institutions need to ensure that the environment in the facility is safe for residents and staff, drugging of residents for behavior control is not appropriate. Brazil should review its procedures for the use of psychoactive medications in institutions to ban their use as chemical restraints and ensure adequate oversight to enforce this ban.

⁵³ Human Rights Watch interview with an institution director, Rio de Janeiro, March 28, 2017.

⁵⁴ Human Rights Watch interview with an institution director, Rio de Janeiro, March 21, 2018

⁵⁵ Human Rights Watch interview with institution staff members, Rio de Janeiro, November 8, 2016.

⁵⁶ Human Rights Watch interview with institution staff members, Rio de Janeiro, November 7, 2016.

⁵⁷ WHO, “Realising recovery and the right to mental health and related services,” WHO QualityRights Guidance and Training Tools, WHO/MSD/MHP/17.4, http://www.who.int/mental_health/policy/quality_rights/guidance_training_tools/en/ (accessed May 5, 2018).

Staff in most institutions visited stated that they regularly gave medicines to adults without their consent. In one institution in Rio de Janeiro, the director said, “We don’t ask for consent because these are persons who have severe disabilities. They don’t speak, they don’t think.”⁵⁸ For adults, medications should be delivered with the consent of the individual being treated. The CRPD Committee has held that treating an adult with medications without consent is a violation of the right to equal recognition before the law and an infringement of the right to personal integrity; freedom from torture and inhuman and degrading treatment; and freedom from violent exploitation and abuse.⁵⁹

Informed consent can be achieved through supported-decision making. Brazil’s law on inclusion establishes a general framework to implement supported decision-making. It should be further developed by establishing accessibility measures and reasonable accommodation (plain language and alternative forms of communication) and advance directives in the appointment of one or more persons who will provide support chosen by the person concerned. See also, below, on Legal Capacity.

For children, consent should be given by the guardian, in consultation with the child, and used only for the therapeutic purposes and consistent with the right to the highest attainable standard of health.

⁵⁸ Human Rights Watch interview with institution director, Rio de Janeiro, March 21, 2018.

⁵⁹ CRPD, arts. 15, 16, 17.



A psychiatric ward in an institution in Rio de Janeiro. Residents of most institutions in Brazil live in depersonalized conditions, have few if any personal belongings, and have little or no privacy.

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Inadequate Education

Human Rights Watch found that education for persons with disabilities in the institutions we visited was limited. The majority of people with intellectual disabilities or who could not communicate received no education at all. Brazil's 2016 Statute for People with Disabilities states that people with disabilities have the right to education and to be provided with support and reasonable accommodations without extra cost in regular schools regardless of where they live.⁶⁰

In four institutions visited in Rio de Janeiro for children and adults with disabilities, residents with intellectual disabilities and other disabilities which required high support,

⁶⁰ Law of Brazil on Inclusion of People with Disabilities (Statute on People with Disabilities), no. 13,146/2015, July 6, 2015, arts. 27 and 28.



A group of children with physical and sensory disabilities drawing while sitting on the floor in a common room an institution in Rio de Janeiro. Drawing is one of the few activities that institution staff facilitate for children and adults with disabilities. © 2017 Human Rights Watch

did not receive any education. In São Paulo, Human Rights Watch visited two institutions for children with disabilities with high support requirements; none of them received education. In an institution for 49 children and adults with intellectual and multiple disabilities in Ceilândia, one person was going to a regular school, the others had not received any schooling. In Bahia, Human Rights Watch visited an institution with 87 children and adults; none of whom received any education.⁶¹ In a second large institution in Bahia of 109 children with disabilities, 37 children, either with autism or high support requirements, or both, did not receive any education.⁶²

The São Paulo's Public Prosecutor's Office's inquiry in 2016 into 16 specialized institutions for children with disabilities in the municipality found that two-thirds of the institutions had no relationship with educational services..⁶³

In the institutions visited by Human Rights Watch, only children whom the institution staff determine have some level of autonomy can attend school. Children with disabilities living in general institutions or who do not have intellectual disabilities are regularly sent to local mainstream schools in local communities. In some cases, children from institutions also

⁶¹ Human Rights Watch interview with institution staff member, Bahia, April 5, 2017.

⁶² Human Rights Watch interview with institution staff member, Bahia, April 5, 2017.

⁶³ São Paulo Public Prosecutor's Office, Civil Inquiry no. 033/2017, vol. 1, p. 97.

attend special schools in the community that are exclusively for children with disabilities rather than in mainstream schools for all children. Some institutions provide children with intellectual or sensory disabilities special education programs within the institution, which has no official status as an educational facility. Children receive a certificate that is not an official diploma and would not allow an individual to continue his or her education elsewhere.

Throughout the interviews Human Rights Watch conducted with institution staff and other government officials, there was a clear tendency to classify persons according to what staff believed was a child's "level of disability," which ranged from moderate to severe. According to staff, in most institutions visited and some policymakers interviewed by Human Rights Watch, those who were deemed to have "severe disabilities" (*muito comprometidos*) were considered not capable of being educated.⁶⁴ Alberto, a 52-year-old man with a physical disability, institutionalized for 40 years, said that he only completed first grade, "I have been living here since I was 12. I managed to study until first grade of primary school. I'm interested in studying physics."⁶⁵

Mariana, an 18-year-old blind woman, had been living in an institution since she was 12 and remained there as the institution was transformed into an inclusive residence. She told Human Rights Watch that she did not know how to read and write and only recently began learning to use braille at the Institute for the Blind in Bahia. She told Human Rights Watch that she wanted to work as a professor or as a physiotherapist.⁶⁶

Clementina Bagno, member of the Guardian Council for Children (Conselho Tutelar) in Brasilia, confirmed that:

General education policies do not consider the requirements of people with disabilities who are living in institutions which leads to their exclusion and marginalization.⁶⁷

⁶⁴ Human Rights Watch interviews with staff in one institution in Rio de Janeiro and two in São Paulo, November 21, 2016.

⁶⁵ Human Rights Watch interview with Alberto [not his real name], an institution, Bahia, April 5, 2017.

⁶⁶ Human Rights Watch interview with Mariana [not her real name], an institution, São Paulo, April 7, 2017.

⁶⁷ Human Rights Watch interview with Clementina Bagno, Brasilia, November 22, 2016.

The CRPD requires state parties to ensure the right of persons with disabilities to education without discrimination and on an equal basis with others through inclusive education at all levels: preschool, primary, secondary, and tertiary school, vocational training and lifelong learning, and extracurricular and social activities.⁶⁸ The CRPD prohibits excluding persons from the educational system on the basis of their so-called “level of disability.” No formal or informal evaluation should be made to determine if a child or an adult with a disability is capable of being educated in the general education system.⁶⁹ Any evaluation should have the purpose of assessing the specific requirements a person needs to fully support him or her in the general education system. The CRC also establishes the right of every child to education.⁷⁰ In its 2015 review of Brazil, the CRPD Committee expressed concern about children with disabilities being refused admission to schools or charged extra fees as well as the lack of reasonable accommodation and accessible school environments in the mainstream education system.⁷¹

An arbitrary determination that a child can or cannot benefit from educational services based on the alleged level of autonomy or disability constitutes discrimination. The state has the obligation to ensure that private persons, included nonprofit organizations, do not discriminate against persons with disabilities, including based on assumptions about their ability to be educated.⁷²

***“Muito Comprometido”?* “Severe disability” has no definition**

Throughout this research Human Rights Watch conducted in Brazil, public officials and institution staff consistently referred to people with certain types of disabilities or with multiple disabilities as having “severe disabilities” (*muito comprometido*). This was usually in reference to people who could not communicate, had difficulties

⁶⁸ CRPD, art. 24. United Nations Committee on the Rights of Persons with Disabilities, General Comment No. 4, On the Right to Inclusive Education, UN Doc. CRPD/C/GC/4 (2016).

⁶⁹ CRPD, art. 24.2.a

⁷⁰ CRC, art. 28.1.

⁷¹ UN Committee on the Rights of Persons with Disabilities, Concluding Observations on the Initial Report of Brazil, CRPD/C/BRA/CO/1, September 29, 2015, paras. 44 and 45.

⁷² CRPD arts., 1, 4, 5, and 24.

understanding and self-functioning, had medical conditions that required intense support, or had multiple disabilities.

Many officials and institution staff seemed essentially to justify a lack of enjoyment of rights and services by certain people, based on this vague and essentially arbitrary concept of “severe disabilities.” The term as they applied it has no clear meaning, and instead seemed to represent a subjective and careless effort to create a category of people who can be stripped of their autonomy and rights. International human rights law protects all persons with disabilities, regardless of the so-called “level of impairment.”



A psychiatric ward in an institution in Rio de Janeiro. Residents of most institutions in Brazil live in depersonalized conditions, have few if any personal belongings, and have little or no privacy.

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Lack of Accessibility in Children's Institutions

Although children with disabilities are placed in institutions, including general institutions for children, for long periods of time, all three general children's institutions visited by Human Rights Watch lacked an accessible physical environment for people with disabilities. In one institution in São Paulo, for example, stairs at the entrance made it impossible for a child with physical disability to enter or exit independently.⁷³ One institution in Salvador had only one bathroom with enough space for a wheelchair to fit, but it was in the girls' section.⁷⁴ No bathroom in any general institution was fully accessible with toilets with raised toilet seats and support bars.



A locked door at an institution for people with disabilities in the outskirts of Brasília, (Federal District). Many institutions for adults with disabilities in Brazil have the look and feel of detention centers, with heavy doors with locks and barred windows in order to keep people inside. © 2016 Human Rights Watch

According to the Technical Guidelines: Reception Services for Children and Adolescents in Brazil, institutions for children should be managed based on the principle of inclusion.⁷⁵ However, 2016 national survey shows that of the nearly 3,000 institutions for children and adolescents throughout Brazil, only 584 have accessible entrances, 767 are accessible in the bedrooms and spaces for common use, and 539 have accessible bathrooms.⁷⁶

⁷³ Human Rights Watch visit to an institution, São Paulo, November 13, 2016.

⁷⁴ Human Rights Watch visit to an institution, Bahia, April 5, 2017.

⁷⁵ Human Rights Watch interview with Judge Reinaldo Cintra Torres de Carvalho, November 13, 2016 and ECA.

⁷⁶ SUAS Census 2016, question 41.