INSISTING ON INCLUSION
Institutionalization and Barriers to Education for Children with Disabilities in Kyrgyzstan
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Locations of residential institutions and special schools visited by Human Rights Watch
Summary

When Adinai was five years old, her mom, Aida Mysalieva, began to worry: unlike other children her age, Adinai did not speak. Aida had every ambition of enrolling her daughter in a mainstream school. But when she was six, a doctor recommended Adinai undergo an assessment by a government-run commission of experts, called the Psycho-Medical Pedagogical Consultation (PMPC). They determined that Adinai was not “fit” for a mainstream school and should study in a residential special school for children with intellectual disabilities instead.

For Adinai, the PMPC’s decision proved final. Aida took her back to the commission two years later in the hopes that they would change their decision and transfer her to a special school for children with speech disabilities, where she would likely have more time to work with a speech therapist. But the commission rejected her request. “They said she couldn’t study there because she was diagnosed with an intellectual disability,” she said. “I cried.”

While the PMPC’s decisions are not legally binding or mandatory, Mysalieva lacked access to information about other options and felt compelled to follow their recommendations, even if it meant segregating her child in a residential special school.

Adinai, now 14, just completed her final year of schooling, but she still does not speak. Her mom said she had received little individual attention or education at the residential special school. Children were taught according to a simplified but standard curriculum, and Adinai fell quickly behind.

Given this lack of progress, Mysalieva is worried about how she will care for Adinai, as she is not be able to afford a caretaker for her daughter, yet does not want to leave her alone at home all day.

“I still hope,” she said. “Each day that she’s growing up I get more scared. She has a tongue, and she has a voice. I just pray to God that she will be able to speak.”
In recent years, the government of Kyrgyzstan has acknowledged the importance of ending the segregation of and discrimination against people with disabilities and has taken foundational steps to enhance protections of their rights. In March 2019, former president Sooronbay Jeenbekov signed a law that made Kyrgyzstan a party to the Convention on the Rights of Persons with Disabilities (CRPD). This followed the government’s preliminary efforts, beginning in 2012, to close or transform 17 out of 140 institutions for children, including children with disabilities. Despite this, approximately 3,000 children with disabilities, like Adinaï, continue to be segregated in residential institutions or special schools where they face neglect, segregation, and discrimination.

Among the numerous pressures on families to place children with disabilities in an institution, discriminatory barriers to education in the communities where they live is a major one. Children with disabilities in Kyrgyzstan are often left no other option but to attend a residential special school or to receive education at home, violating their right to inclusive education. Children who are taken out of state residential institutions or schools still struggle to access inclusive education at schools in their communities.

This report is based on in-person visits to six institutions for children with disabilities and 111 interviews with children with disabilities, their parents, institution staff, and experts in four regions of Kyrgyzstan. It describes abuses in state care as well as barriers to education that often lead to a child’s segregation in a residential institution or special school, or their isolation at home. These barriers include discrimination in enrollment, schools that are not physically accessible, and failure by schools to provide an individualized approach or reasonable accommodations—an adjustment or support allowing a person to fully enjoy their rights on an equal basis with others.

Kyrgyzstan’s stated commitment to close or transform several residential special schools is an important first step toward bolstering protections for children with disabilities. But for deinstitutionalization to succeed, the government should guarantee access to quality inclusive education for all children in the communities where they live, regardless of their disability, and ensure access to community-based services.
Life in Institutions

There are several types of state residential facilities for children with disabilities in Kyrgyzstan, including residential special schools overseen by the Ministry of Education and Sciences and Psychoneurological Social Residential Institutions (“psychoneurological institutes” or “PNIs”) overseen by the Ministry of Labor and Social Development.

For many, placing children with disabilities in residential institutions or special schools might be with the aim of protecting and providing them “specialized” medical attention and education. However, in practice, this can amount to institutionalization, stripping children with disabilities of the fundamental rights to family life, to living in their communities, and to a quality, inclusive education. Institutionalization and separation from family can deny children essential personal attention and have an overall negative impact on a child’s physical, emotional, and intellectual development.

In all six residential institutions and special schools for children with disabilities Human Rights Watch visited, researchers documented insufficient personnel to care for the large number of children, particularly those with higher support needs, resulting in neglect and lack of individualized attention and care.

Several residential institutions and special schools relied heavily on volunteer support to compensate for gaps in personnel, but this approach is unsustainable, as positions are more vulnerable to shifts in volunteer group resources or unforeseen circumstances. For example, during the Covid-19 pandemic volunteers were unable to visit institutions for several months, and children at one institution were unable to receive any kind of educational services as a result.

In addition to being places where children with disabilities are segregated from society, children within these institutions are segregated according to type of disability: children may be divided up into a “walking group,” “crawling group,” and a “lying-down group” according to their physical disability. As a result of these practices, they have few, if any, interactions with people other than the children in their group and their caregivers. Segregation on the basis of disability is a discriminatory practice.
Human Rights Watch found evidence that staff in institutions and residential schools often used psychotropic medications or forced psychiatric hospitalization as a means of managing behavioral issues in children with disabilities. These medications appeared to be dispensed with minimal oversight, and without explanation of their intended use at the time. Such practices raise serious concerns about the appropriateness of these treatments, and the apparent lack of consent from children and parents in their use.

At one institution, medical staff said they gave children Aminazin (an antipsychotic) “whenever aggressive behavior arises.” Another medical worker said Aminazin was also used “during the hormonal period for boys,” in order to suppress their libido. Medical staff at these institutions mentioned that in cases where children required particularly high doses of psychotropic medications, they sent them instead to psychiatric hospitals. “We had one boy who was very aggressive—I sent him to the psychiatric hospital for three
“months,” said one doctor. “There they can even overdose on sedatives, but they have an intensive care unit so they can resuscitate them.”

Children with disabilities in institutions in Kyrgyzstan have no true safeguards against physical or psychological violence. None of the institutions visited by Human Rights Watch had accessible and confidential complaint mechanisms for children in place, and in at least three institutions children were banned from contacting parents or guardians without staff supervision.

Children with disabilities in psychoneurological institutes are also denied access to any formal schooling. This is both contrary to Kyrgyzstan’s Law on Education, which states that all Kyrgyz citizens have a right to education regardless of disability, and to their right to education enshrined in international human rights law. Children with disabilities who are placed in residential special schools often receive segregated, substandard education and minimal individualized attention, limiting their long-term educational and professional opportunities.

Human Rights Watch found that without outside intervention by nongovernmental organizations (NGOs), upon turning 18, children in psychoneurological institutes are routinely by default stripped of their legal capacity and denied the right to make decisions about where they live, work, and what medical care they receive. They are either transferred automatically to an adult institution which by law will assume guardianship over them, or guardianship is granted to a parent or relative.

In light of the abuses documented above, Human Rights Watch urges the Kyrgyz government to guarantee access to inclusive education and to further develop community-based services in order to move children with disabilities out of institutions and into families in communities, with a goal of ending institutionalization altogether.

The Kyrgyz government has made very little progress implementing its 2012 deinstitutionalization plan, particularly as it pertains to children with disabilities. At present, only three out of 16 federally controlled residential special schools are slated for closure as part of the plan, and only one of those three has closed. Furthermore, the overall number of children in institutions has increased in recent years, while there has been no noticeable decline in the number of children with disabilities in institutions.
In 2014, an updated version of the deinstitutionalization plan deliberately excluded psychoneurological institutes. Individuals involved in the plan’s development said these institutions were excluded because they represented the most “difficult cases.” Any plan to end institutionalization that does not guarantee the rights of all children with disabilities to live in their communities on an equal basis with other children—regardless of the type of disability—is discriminatory.

Barriers to Education in the Community

A number of factors play a role in a parent’s decision to place their child in an institution. Children with disabilities lack free and adequate access to various important services in their communities, from speech therapy and sign language courses to many kinds of early educational intervention and opportunities. For many parents, however, the moment they decide to enroll their child in school is a decisive one. Discrimination, the lack of reasonable accommodations in mainstream schools, and other barriers that block a child’s entry into a school in the community often accelerate their placement in an institution.

Two systems, both of which are meant to facilitate a child’s learning and development, actually serve as barriers to their enrollment. When they reach school or pre-school age, children with disabilities should undergo the Psycho-Medical Pedagogical Consultation (PMPC), which is overseen by the Ministry of Education and Sciences and provides guidance on a child’s educational path. However, experts and parents of children with disabilities said that the PMPC often effectively blocks a child’s entry to mainstream schooling. Human Rights Watch found that some parents, when able to access alternative information from an NGO, parent groups, or online forums, could enroll their children in schools despite decisions by the PMPC recommending special school or home education. But parents who lacked alternative information said they felt compelled to follow the commission’s recommendations, resulting in the segregation of their child either in specialized schools or at home.

Because there are very few PMPCs in the country, particularly in rural areas, many parents relied instead on documents from the Medico-Social Commission of Experts (MSCE) when enrolling their child in school. The MSCE is overseen by the Ministry of Labor Social Development and is conducted entirely by medical experts. They assess the child’s health
and disability, develop a medical and rehabilitation program, and also play a role in
determining what disability benefit payments a child’s family will receive. As part of its
assessment, the MSCE also makes a determination about the educational potential of the
child which can include a conclusion that a child is “not capable of education,” or only
qualified for special education. While a representative of the MSCE told Human Rights
Watch that the evaluation was meant only to aid the PMPC and should play no role in a
child’s educational path, parents in rural areas where there was no PMPC said that schools
used the MSCE’s evaluation to discriminate against them and block them from enrollment.
Denying a child access to an inclusive education in this manner violates Kyrgyz law and
Kyrgyzstan’s international human rights obligations.

Even in cases where a child was allowed to enroll full or part-time in a mainstream school,
their attendance there was often insecure and subject to arbitrary termination. Parents
said some school directors implied that enrolling children contrary to a recommendation
by the PMPC or MSCE was a violation of the law, and otherwise made it clear that they were
doing the parents a favor by allowing the child to attend. This led to an abrupt termination
of studies in some cases when school directors’ willingness to enroll a child changed and
children were asked to leave.

Human Rights Watch interviewed parents of 10 children who were receiving home
education. While all 10 said a teacher came at least a few times per week to teach their
child, their children received as little as one-and-a-half total hours of education at home
per week, compared with the 20 to 33 hours children get if they attend a mainstream
school. Parents said that they did not believe their children were receiving a quality
education. In almost all cases, home education served as a way of segregating children
with disabilities on a long-term or permanent basis rather than as an exceptional and
temporary measure for children whose health did not allow them to attend school, in
accordance with international human rights standards.

For example, Human Rights Watch documented how a teacher visited Omurbek, an 11-year-
old boy with cerebral palsy, for only 30 minutes three times per week. While at first the
teacher’s visits were longer and more frequent, over time, she reduced them significantly.
“She says half an hour is enough for ‘these kinds of children’,” his mother told Human
Rights Watch. Omurbek is in his fourth year of home education.
Without inclusive quality education in mainstream schools and adequate information for parents about the right to inclusive education, children with disabilities will remain at risk of being segregated in residential institutions or isolated in the confines of their home, receiving poor or no education.

The Kyrgyz government issued a “Concept on Inclusive Education” in July 2019 that, if carried out in a timely manner and with adequate funding, could prove an important step toward making inclusive education a reality in Kyrgyzstan. So far, the government has not passed any more detailed plans or legislation to implement the vision of the concept paper.

As a party to a number of human rights treaties, including CRPD and the Convention on the Rights of the Child (CRC), Kyrgyzstan has an obligation to ensure the full participation of children with disabilities in society, including by ensuring no child is separated from his or her family on the basis of their disability. Kyrgyzstan should guarantee access to inclusive education for children regardless of disability, implement a time-bound plan for deinstitutionalization, increase support for children with disabilities to live with their families in the community, and ensure that persons with disabilities enjoy the right to legal capacity on an equal basis with others. For as long as children with disabilities remain in state institutions, Kyrgyzstan authorities must protect them from abuse.
Key Recommendations

Human Rights Watch urges the government of Kyrgyzstan to take the following steps as a priority:

Protect children and young people with disabilities in institutions from harm and abuse by:

- Ending the use of inappropriate medication or placement in a psychiatric hospital as a means of punishing a child or controlling their behavior;
- Ensuring that children with disabilities who remain in institutions pending deinstitutionalization have access to inclusive education, adequate health care, rehabilitation, and play;
- Creating accessible and effective mechanisms for children with disabilities in state institutions to report abuse without risk of repercussions;
- Ensuring the right to legal capacity, including an end to formal or informal policies or practices that deprive children with disabilities in institutions their legal capacity upon reaching adulthood, and guaranteeing that young people aging out of institutions can participate in court decisions concerning them, such as regarding their legal capacity, and can receive legal assistance in such court processes.

Implement a time-bound process for deinstitutionalization, including by:

- Eliminating discrimination in the deinstitutionalization process, including by guaranteeing that the national deinstitutionalization policy include children with disabilities equally with other children and include the views of children with disabilities;
- Ensuring support for children with disabilities to live with their families, or in other family settings in the community including by beginning to redirect financial and other resources away from institutions and to children with disabilities, their families, and the establishment of community-based services.
End discrimination in education by:

- Guaranteeing access to quality inclusive education for children with disabilities on an equal basis with others, including through the provision of reasonable accommodations, in line with the government’s international obligations;
- Abolishing the PMPC and redirecting funds to schools or school districts to create dedicated professional teams to identify the reasonable accommodations necessary to meet individual requirements;
- Prohibiting the MSCE or any other body from labeling children as ‘uneducable’ or otherwise categorizing them according to supposed capacity to learn and prohibiting the use of an MSCE evaluation to formally or informally deny a child access to inclusive education;
- Improving access to information for children with disabilities and their parents about the right to inclusive education and the role of the PMPC and the MSCE.
Methodology

Human Rights Watch conducted field research for this report between October 2019 and February 2020, in Chuy, Jalalabad, and Batken regions, and in Osh city. Follow-up interviews with disability rights experts, families of children with disabilities, and young adults with disabilities were conducted by phone between February and July 2020. Human Rights Watch researchers interviewed a total of 111 people for this report.

Human Rights Watch interviewed 24 children and young people between ages 14 and 35 who were currently or previously living in residential institutions or special schools for children with disabilities. Out of this number, 10 were former residents of institutions for children with disabilities between the ages of 20 and 35. Eleven were children under age 18 currently living in residential institutions or special schools for children with disabilities, and three were young adults ages 18-19 still living in these institutions. Five interviews with children inside institutions or residential special schools were conducted in the presence of institution staff.

Human Rights Watch further interviewed four children with disabilities under the age of 18, in two cases with a family member present. Human Rights Watch interviewed two adults with disabilities about their inability to access education.

Human Rights Watch also interviewed 27 parents of children or young adults with disabilities between the ages of eight and 18 who were receiving some education. This included 10 parents of children who received home education or home education with partial attendance of school. It included five parents of children who were enrolled in mainstream schools, and five parents of children who attended special day schools as well as three parents of children currently attending residential special schools. This also included four parents of children who had been taken out of an institution. Human Rights Watch interviewed one parent of a 15-year-old girl with a disability who was not receiving any education, and the parent of one older adult, aged 33, with a disability who had not received any education.
Human Rights Watch visited six residential institutions and special schools for children with disabilities, including two psychoneurological institutes, three residential special schools for children with intellectual disabilities, and one residential special school for blind children. These institutions were selected because of their relative proximity to large cities and because they housed children with different types of disabilities. Two of these visits, to psychoneurological institutes, where 364 children live and which do not have any official educational component, were organized by the Ministry of Labor and Social Development. The visits to the residential special schools, which fall under the Ministry of Education, were facilitated by Kyrgyzstan’s Ombudsman, a human rights oversight body appointed by parliament. The Ministry of Education did not react to letters in December 2019 requesting help in organizing visits to these institutions.

At these residential institutions and special schools, we interviewed 39 staff members, including: institution directors, teachers, caretakers, nannies, doctors, nurses. Unfortunately, in some residential institutions and special schools, directors or staff repeatedly interrupted interviews with children or other staff members, undermining the privacy of these interviews.

Human Rights Watch took great care to interview people in a manner that respected their rights and dignity, and maximally ensured that the interviews took place in a location where interviewees’ privacy was protected. In all cases, Human Rights Watch told interviewees they would receive no personal service or benefit and that the interviews were completely voluntary and confidential. One interviewee was compensated for transportation services because meeting with a Human Rights Watch researcher was in a different part of the city from her home. Participants were informed that they could discontinue the interview at any time or decline to answer any specific questions without consequences.

Unless otherwise noted, we have used pseudonyms for all children and young people currently or previously living in institutions or residential schools in order to protect their privacy. We have also withheld names and other details from some institution staff for their protection from possible reprisals.
In February 2020, Human Rights Watch met with representatives from the Ministry of Labor and Social Development. Human Rights Watch also requested a meeting with the Ministry of Education during the same period but did not receive a positive response.

On May 21, Human Rights Watch sent letters presenting preliminary findings of this report and requesting information from the Ministry of Labor and Social Development, the Ministry of Education, the Ministry of Health, and the Ministry of Justice. Human Rights Watch received a preliminary response from the Ministry of Labor and Social Development on June 21 but did not receive responses from any other ministries.

Human Rights Watch interviewed staff or representatives of 15 nonprofit or international organizations, including: organizations supporting parents with children with disabilities, organizations supporting young people with disabilities, organizations supporting women with disabilities, and organizations supporting former residents of institutions for children with disabilities. Human Rights Watch interviewed, either by phone or in person, staff from the United Nations Children’s Emergency Fund (UNICEF) in Bishkek, Open Society Foundation-Kyrgyzstan, and the European Union (EU) delegation in Bishkek.

All interviews were conducted in Russian or English or were translated from Kyrgyz or Uzbek into Russian by an interpreter.
I. Background

Institutions in Kyrgyzstan

There are more than 140 residential institutions and schools for children in Kyrgyzstan for children with and without disabilities. As of 2019, more than 12,000 children were living in state-run institutions and schools, and most of those children had at least one living parent. Of these children, approximately 3,000 live in residential institutions or special schools for those with disabilities.

There are several types of state residential facilities for children in Kyrgyzstan. The Ministry of Education and Science oversees any state institution that contains an educational component. These include schools that serve children without disabilities: there are 33 mainstream state residential or “boarding” schools and 13 residential schools for children without parental guardians. According to an 2018 Organisation for Economic Co-operation and Development (OECD) report, chronic poverty is the main factor driving enrollment in these institutions, particularly as they “account for the majority of social services provided in Kyrgyzstan.” High rates of migration also appear to be playing a role. In 2016, UNICEF concluded that children of parents who migrate “are often left with relatives, and in many cases with grandparents who may struggle meeting the needs of growing children, many of whom are placed in residential institutions.” Human Rights Watch did not visit any institutions for children without disabilities.

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2 As of September 2020, the Ministry of Labor and Social Development's list of institutions for children and the number of residents stated that there were 2,871 children at federal institutions or residential special schools for children with disabilities, though this does not include children at several residential special schools that are under municipal rather than federal control: Ministry of Labor and Social Development, “List of Children's Residential Institutions of all Types of Ownership in the Kyrgyz Republic,” http://child.mlsp.gov.kg/shelters.php (accessed Sept. 1, 2020).
The Ministry of Education also oversees 16 residential special schools for children with disabilities, where children enroll from six or seven to 14 or 17 years old. These schools typically group children on the basis of their disability. There are schools for blind, schools for deaf children, schools for children with intellectual or psychosocial disabilities, and schools for children with speech disabilities. Human Rights Watch found that in residential special schools, a majority of children had connections to their families and would go home, in some cases every weekend, but mostly every few weeks or on school holidays.

The Ministry of Labor and Social Development oversees residential institutions for children where there is no educational component. These are called Psychoneurological Social Residential Institutions (“psychoneurological institutes” or “PNIs”), where children typically live from four to 18 years old. Compared to most children in residential special schools, when families place a child in a PNI they transfer guardianship rights to that institution. Human Rights Watch found that children in these institutions were much less likely to have regular connection to family and more likely to spend all their time there. Children admitted to these facilities typically have physical, intellectual, and psychosocial disabilities that require greater support. Unlike residential special schools, PNIs provide comprehensive medical services on-site.

In addition to state institutions and residential schools, there are 54 private and religious institutions, as well as 17 residential schools, including those for children with disabilities, that fall under municipal, rather than federal, control.

Deinstitutionalization Efforts

In 2012, Kyrgyzstan unveiled a plan to transform or close residential institutions for children by 2018, called the “Resolution on the Optimization of the Management and

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Financing of Residential Institutions for Children of the Kyrgyz Republic.”

Originally the plan called for the closure of 19 institutions or residential schools, both for children with disabilities and those without, though that number was later reduced to 17. The plan also calls for measures to reduce the number of children entering institutions, such as improving access to information for parents who are at risk of giving up their child, including at hospitals. It calls for improving conditions within institutions, specifically by installing “sensory rooms,” workshops and computer equipment for children with disabilities, increasing social support and integration for children both during and after institutionalization, and improving staff training.

The plan is backed financially by the EU, which made 26 million euros (approximately US$31 million) in budgetary support conditional on its implementation, and which has also contracted several NGOs to monitor and support the transfer of children out of institutions. The main objective of the project, according to public statements, is to “support the government and civil society to reduce poverty, to ensure access to social services for vulnerable sectors of the population, and to enhance public accountability, good governance and transparency in public spending.”

While the deinstitutionalization plan lagged in the initial years of implementation, after 2016, Kyrgyzstan began taking steps to reduce the number of students enrolled in several residential schools and transformed them into mainstream schools, including one residential special school for children with disabilities, the Orto-Suu Residential Special School for Children with Intellectual Disabilities.

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10 Ibid.


12 Human Rights Watch phone interview with a European Union official (name and details withheld), Nov. 13, 2019.


Kyrgyzstan's deinstitutionalization efforts have stagnated, resulting in an increase in the number of children who are institutionalized and the number of institutions, from 10,908 at 117 institutions in 2012, to 12,002 children at 143 institutions as of 2019. The Ministry of Labor and Social Development increased spending on residential institutions every year between 2011 and 2015.

In addition to deinstitutionalization, the government has agreed to provide financial support for families of a child with a disability. In January 2019, the government began providing monthly payments of 4,900 som (approximately US$57) to parents or other close relatives under the age of 65 who served as “personal assistants” to a child with a disability, a role that involved ensuring the health, physical rehabilitation, hygiene, feeding and other needs of the child. While this only applied to children who had disabilities that left them “in need of constant care,” which parents said disqualified children without physical disabilities, and to parents who were otherwise unemployed, some parents interviewed for this research said the payment did provide them with some relief. According to the Ministry of Labor and Social Development, 6,467 people were receiving payments as “assistants” for children with disabilities as of January 1, 2020.

Government Approach to Deinstitutionalization

While the government of Kyrgyzstan has committed to moving children out of 17 residential institutions or schools and into family environments, only three of these 17 are residential special schools for children with disabilities. So far, the government has fully transformed only one residential special school, the Orto-Suu Residential Special School.

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19 Letter of preliminary response to Human Rights Watch from the Kyrgyz Ministry of Labor and Social Development, Received June 22, 2020.
for Children with Intellectual Disabilities, into a mainstream school, though almost half of the students were transferred to other institutions. The government has begun the transformation of two other residential special schools, Krasnaya Rechka Residential School for Orphan Children with Intellectual Disabilities, and the Dmitrievka Residential Special School for Children with Intellectual Disabilities, both of which Human Rights Watch visited. Both schools said they had implemented a moratorium preventing new children from enrolling at the beginning of the school year. The director of Dmitrievka school said that 10 children had left the school at the beginning of the year, some of them as part of the deinstitutionalization initiative.

Two psychoneurological institutes for children with disabilities, which were originally part of the transformation effort, were explicitly excluded from the plan in 2014. One international official involved in executing the plan said that these institutions were excluded because they housed “the most difficult cases,” meaning children with certain types of disabilities. Another representative of an NGO involved in implementing the deinstitutionalization plan said that the government postponed the closure of institutions for children with disabilities, focusing on institutions for children without disabilities instead.

All of the above gives rise to concerns that the government may not be sufficiently prioritizing the reunification of children with disabilities with their birth families or identifying alternative care solutions for them. The failure to undertake deinstitutionalization of children with disabilities on an equal basis with other children constitutes discrimination. The exclusion of psychoneurological institutes from the deinstitutionalization process is particularly disconcerting given that many children living in them are automatically transferred to institutions for adults upon turning 18, a process which will be detailed further in this report.

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24 Human Rights Watch phone interview with international official (name withheld), November 13, 2019.
The mechanisms used to place children in institutions differ, and the barriers to placing a child with a disability in institutional care are significantly lower than those for other children. In 2012, Kyrgyzstan’s new “Code on Children” mandated that there must be a court decision if a child is placed in an institution for more than six months. However, this requirement does not apply to children with disabilities, who may be placed in an institution long-term based on a decision by a government commission of medical or teaching experts alone.

Inclusive Education

According to official statistics, almost 1.5 million children were studying in mainstream schools and pre-schools in Kyrgyzstan in 2018. There are an estimated 32,000 children with disabilities in the country, and the government states that 2,000 children with disabilities do not receive any kind of education. However, according to statistics from the Ministry of Education and Science shared with UNICEF, the number is actually much higher: only 10,925 children with disabilities are known to be receiving education of any kind.

Even among those children with disabilities receiving an education, it is clear that many are segregated either in special schools, or isolated and receiving home education. According to official statistics, 3,390 children were studying in special residential or day schools in 2019. In 2019, then-Minister of Education Gulmira Kudayberdieva said in an interview that 200 children with disabilities were studying in “remedial classes” that took

29 Letter of preliminary response to Human Rights Watch from the Kyrgyz Ministry of Labor and Social Development, Received June 22, 2020.
place within mainstream schools but separate from classes for children without disabilities. According to Kudayberdieva, only 305 children with disabilities were enrolled in mainstream schooling.\textsuperscript{33}

The Kyrgyz government has been supported by a number of international organizations in implementing projects on inclusive education. In 2018, UNICEF announced that with the support of USAID it would support 10 “pilot schools” with inclusive education, where children with disabilities attend classes with their peers.\textsuperscript{34} The pilot programs began operating in September 2019. In order to ensure that children with disabilities in surrounding communities are enrolled in these pilot schools, UNICEF provided them with protocols for identifying and monitoring children with disabilities in the community.\textsuperscript{35} The EU has also pledged 35 million euros (US$41 million) in budgetary support for Kyrgyzstan to build up inclusive, equitable, and quality education, including by improving policy-making capacities and enhancing the professional development of teachers.\textsuperscript{36} This is in addition to the 26 million euros to support the deinstitutionalization process.

In July 2019, the Kyrgyz government adopted the “Concept on the Development of Inclusive Education in the Kyrgyz Republic from 2019-2023,” which was developed with the help of leading disability rights groups and which has the backing of USAID and UNICEF as well.\textsuperscript{37} The concept’s primary goals include “improving legislation in the sphere of education for those students with special educational needs,” “developing, piloting, and implementing mechanisms for the development of inclusive education,” and “implementing necessary pedagogical knowledge, skills, and technologies in the system of preparation and training


of staff.” To date, no legislation has been passed as part of this concept.

II. Abuses in Institutions and Residential Special Schools

Human Rights Watch visited six residential institutions and special schools for children with disabilities in Osh, Chuy region, Jalalabad region and Batken region. Human Rights Watch found that children and young persons with disabilities experience a range of situations in which their human rights are violated in state care in Kyrgyzstan. Human Rights Watch identified a number of serious problems with regards to state residential institutions and special schools in Kyrgyzstan, including segregation, the overuse of psychotropic medications and forced psychiatric hospitalization, neglect, lack of safeguards from physical and other abuse, and lack of access to quality or, in some cases, any education. Children in PNIs are also often denied legal capacity upon reaching adulthood.

Living in institutions creates serious emotional hardship for children. Numerous observational studies have documented the negative impact on physical, intellectual, emotional, and social development among children separated from their families and placed in institutions.\(^{39}\)

Neglect

Lack of individualized attention from caregivers was a significant problem in all institutions Human Rights Watch visited. This was due in part to the lack of qualified personnel to care for large numbers of children with disabilities. In many residential institutions and special schools, one caregiver was responsible for 15 to 25 children at a time, many of whom might have high care needs. Research has shown that the absence of one-to-one relationships with a primary caregiver is a major cause of harm to a child’s development and cause of attachment disorders.\(^{40}\)

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Staff at all institutions said they developed “individual plans” for each child, with expectations for what the child could learn to achieve on a monthly or yearly basis, from educational accomplishments to basic self-care. But personnel at institutions said that the limited staffing made implementing these plans difficult.

In the Jalalabad Psychoneurological Institute, one caretaker works with two nannies to care for 26 children in the “lying-down” ward where most children had cerebral palsy. Out of 26 children, 21 were lying in beds or cribs when Human Rights Watch visited, and the caretaker said only the few children who are able to sit up in a wheelchair are ever taken outside. The caretaker said that after waking the children up, she would take aside two or three of them and work with them on improving motor, speaking, or other skills for a couple of hours in the mornings. However, she said there were not enough personnel to make these sessions more intensive or to allow her to work regularly with all children in her care.

“There’s not enough of me to go around, each one wants attention, they want to talk to me, sometimes they'll cry without stopping,” she said. A former kindergarten teacher, she had little training in how to educate children with disabilities and had once badly hurt her back by lifting a child, though she said in recent years volunteers had organized a few trainings. “I have no specific approach; I go by instinct and by what I know.”

In the psychoneurological institutes, volunteers from nonprofit organizations or the community filled a crucial gap where staff was lacking. Volunteers and staff of nonprofit organizations carried out vital functions such as physical therapy, massages, and almost all of the basic education that is provided to several children. Reliance on this kind of external support is problematic because it can be more easily interrupted by unforeseen circumstances. For example, during the Covid-19 pandemic, all outside volunteers or nonprofit employees were barred from visiting these institutions. The director of one PNI told Human Rights Watch that whereas five or six volunteers from a nonprofit organization visited twice a week to conduct the services mentioned above, none of those volunteers

41 Human Rights Watch interview with caretaker (name withheld) in Jalalabad Psychoneurological Institute, Jan. 29, 2020.

42 Human Rights Watch interview with directors of both Belovodsk (Feb. 4 2020) and Jalalabad (Jan. 29, 2020) Psychoneurological Institutes.
have been able to visit since March. Of the rudimentary education provided to some
students she said, “There are no classes because there are no volunteers.”

There were other important ways in which lack of staff negatively impacted students’
development. Human Rights Watch documented an acute lack of speech therapy,
particularly in residential special schools for children with intellectual disabilities. In these
schools, many children had difficulty speaking. At one school, 42 of 93 students were
formally diagnosed with speech disabilities, and yet the school budget allowed for only 10
hours of speech therapy for all children each week. At the Uch-Korgon school for children
with intellectual disabilities, one caretaker said that only two or three of the 18 children in
her second-grade group could speak at all. “It would be good if they could spend more
time with the speech therapist, but the staffing hours don’t allow for that,” she said.

In addition to likely leading to delayed development for children, the lack of individualized
attention has had a lasting emotional impact on former residents, most of whom said they
had not formed any close attachments to staff at institutions, where in some cases they
spent more than a decade. Asel N., a 25-year-old woman who uses a wheelchair and who
lived in an institution in Chuy region from 2004 to 2015, said that she had not built a close
connection with anyone there:

“There is one caretaker for everyone—she doesn’t have time to care for all
26 children [in her ward].”

Many of the caretakers Human Rights Watch interviewed spoke affectionately about the
children in their care, but still referred to the children as “sick,” as did other institution
staff. In one institution a caretaker said, “They are sick, all they want is to eat and
breed.” In another institution the caretaker said of those children who couldn’t speak,
“All they do is eat and shit.”

43 Human Rights Watch phone interview with Damira Alimzhanova, Director of the Jalalabad Psychoneurological Institute,
44 Human Rights Watch interview with caretaker (name withheld) at Uch-Korgon School for Children with Intellectual
Disabilities, Jan. 31, 2020
46 Human Rights Watch interview with a caretaker (name withheld) in Belovodsk Psychoneurological Institute, Feb. 4, 2020.
47 Human Rights Watch interview with a caretaker (name withheld) in Jalalabad Psychoneurological Institute, Jan. 29, 2020.
These disparaging and insulting ways of speaking underscored the caretakers’ belief that these children lacked intelligence or social awareness and that there was no point in investing effort in their development.

Referring to one girl sitting within earshot in the same room, a caretaker at Krasnaya Rechka residential special school said, “She’s degrading, her brain is drying up.” The caretaker said the girl’s mother was “also like her, not normal”—meaning she had a disability. When the Human Rights Watch employee expressed concern that these things were being said in front of the child, the caretaker responded, “She doesn’t understand what we're saying.”

Segregation and Lack of Access to Play and Recreation

In the Belovodsk and Jalalabad Psychoneurological Institutes, children were divided into separate wards according to disability. In both cases, the staff referred to these as “walking groups” divided by gender, “crawling” groups, “lying-down” groups, and “unruly” or “difficult” groups, which signified children with intellectual or psychosocial disabilities who had higher support needs. While children in the “walking” or “crawling” groups had access to toys and various activities, most children in the “lying-down” group were lying down in cribs in rooms that were empty but for a television. During Human Rights Watch’s visit to the Belovodsk Psychoneurological Institute, children from the “difficult” group were lying on mats on the floor watching television without any toys in the room. Staff said there was a playroom in the ward, but it was locked at the time.

In several institutions and special schools visited by Human Rights Watch, it appeared that children had few or no personal belongings, including toys or education materials. In the Uch-Korgon residential special school, for example, there were 15-18 beds per room. Staff said that each child had a bedside table for their personal items, but Human Rights Watch saw only a few such tables in each room. A caretaker at the institution said, “They [the children] play outside. They don’t have toys because they fight [over them].”

48 Interview with a teacher (name withheld) at Krasnaya Rechka residential special special school, Feb. 5 2020.
49 Human Rights Watch interview with a caretaker (name withheld) at the Uch-Korgon residential special School, Jan. 31, 2020
In the three residential special schools for children with intellectual disabilities that Human Rights Watch visited, the school was located in a separate building from the dormitories, and hence children could roam freely outside as long as they stayed on the grounds of the institution. In the three other institutions and special schools visited, access to outdoors was more limited, but varied across institutions. For example, one girl who used a wheelchair at the Belovodsk Psychoneurological Institute said that she could go outside whenever she wanted, though it was impossible to interview children in other wards to determine whether they had similar access.\(^5\)

At the Jalalabad Psychoneurological Institute, staff said that children with physical disabilities were not allowed out in winter at all, and during the summer they were allowed out only if they could sit up in a wheelchair.\(^6\) In the Osh School for the Blind, one child said she was not allowed to go outside at all. “Even in the summer they make us play in the gym. I want to go outside because the weather is nice,” said Aigerim A., a 15-year-old girl at Osh School for the Blind. “They don’t like the children moving around too much.”\(^7\)

In all institutions, children were not allowed to leave the grounds of the institution without permission from staff.

**Involuntary and Potentially Inappropriate Medical Treatment**

The two psychoneurological institutes visited by Human Rights Watch had multiple doctors and nurses onsite and were therefore able to provide comprehensive medical and rehabilitation services, including prescription of medication, without sending residents to an outside hospital. The staff at these institutions said they often used psychotropic and other medications, mainly antipsychotics, sedatives and tranquilizers, antidepressants, and mood stabilizers, in ways that seemed primarily aimed at controlling the behavior of residents rather than serving a legitimate therapeutic purpose.

In the residential special schools visited by Human Rights Watch, there was typically only one doctor or nurse onsite who provided basic medical services, which typically did not

\(^{50}\) Human Rights Watch interview with a resident (name withheld) at Belovodsk Psychoneurological Institute, Feb. 4, 2020.

\(^{51}\) Human Rights Watch interview with a caretaker (name withheld) at the Jalalabad Psychoneurological Institute, Jan. 29, 2020.

include the prescription or provision of medications. Staff at these schools said they outsourced more serious medical care to outside facilities. At two of these schools, staff said they regularly sent children to psychiatric hospitals as a way of managing behavior the staff deemed difficult. Children at these residential special schools spent up to one month at a time in psychiatric hospitals and were prescribed psychotropic medication while there.

**Chemical Restraints: Overreliance on Psychotropic Medication to Control Behavior**

In the two psychoneurological institutes visited by Human Rights Watch, staff said they relied on psychotropic medications delivered by the institution’s medical staff to control residents’ behavior. The regular and frequent use of antipsychotics and sedatives in children suggests that these medications may be being used as a chemical restraint and not always for specified therapeutic purposes.

For example, a pediatrician and nurse at one PNI with children as young as five-years-old said they regularly prescribed psychotropic medications including Aminazin, an antipsychotic, which the pediatrician said was used “whenever aggressive behavior arises,” though the nurse said that they did not use this drug in younger children, who were prescribed a barbiturate, Phenobarbital, instead. The staff did not specify what they considered to be aggressive behavior. The pediatrician said Aminazin was also used “during the hormonal period for boys,” and that male residents were given tablets for four to five days straight to suppress their libido.

At another PNI, where children as young as four-years-old live, the resident doctor said the facility tried to limit the amount of psychotropic medications they prescribed because they did not have a psychiatrist onsite. However, the doctor said they nonetheless gave occasional injections of Aminazin to children, “particularly for girls who have a difficult transitional period [i.e. puberty].”

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55 Ibid.
56 Human Rights Watch interview with doctor (name withheld) at Belovodsk Psychoneurological Institute on Feb. 4, 2020.
Aminazin is a brand name of chlorpromazine, an antipsychotic drug used to treat schizophrenia, sleep disorders, and strong pain. The known side effects of Aminazin are significant and include drowsiness, fatigue, depression, helplessness, indifference, lack of motor control, and incessant tremors. There is also a risk of liver damage. The use of antipsychotics to treat adults with intellectual disabilities for “challenging behavior” is widespread and can lead to adverse health consequences. The American Academy of Child and Adolescent Psychiatry has said the use of such medications in children may lead to adverse effects on neurological development, personality and character, including weight gain or movement disorders. Alternative interventions to medications are especially important when there are serious side effects that occur, the Academy said.

Former residents of PNIs said they often saw Aminazin given in injection form by medical staff at institutions to calm children down when they were misbehaving. “[They gave it to them] when they weren’t obeying the caretaker,” said Bakyt K., a 26-year-old man who uses a wheelchair. “They became very sleepy.”

Former residents speculated that limited staffing contributed to the use of antipsychotics in children, as caretakers were already stretched thin and were unable to manage children when behavioral problems arose.

Ruslan P., a 24-year-old with a speech disability who lived in state institutions from birth until age 21, said he regularly saw children being given injections or pills “So that they would sleep—they [the caretakers] couldn’t have done without it, there were too many children to take care of,” he said.

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Some medical staff at these institutions mentioned that in cases where they wanted to administer particularly high doses of psychotropic medications to children, they sent them instead to psychiatric hospitals. “We had one boy who was very aggressive—I sent him to the psychiatric hospital for three months,” said one doctor in the Jalalabad Psychoneurological Institute. “There they can even overdose on sedatives, but they have an intensive care unit so they can resuscitate them.”

Forced Psychiatric Treatment as Punishment

At two residential special schools in Chuy region, where 93 and 132 children lived respectively, staff said that in response to behavioral issues they sent children to the psychiatric hospital in the village of Ivanovka, where, with approval from a local psychiatrist, they were able to hospitalize the children for up to a month every six months. The behavioral issues that staff mentioned as warranting hospitalization included beating up other children, “acting nervously” [нервничают], shouting, and wetting the bed.

Staff at one of these residential special schools showed Human Rights Watch recent medical documents from the Ivanovka hospital, which showed that two children with Down’s Syndrome, both under the age of 11, were treated with daily injections of Aminazin or Azaleptol, a brand name of Clozapine, also an antipsychotic, during the month they were there. Three former residents of these institutions said that they had been repeatedly punished by being sent to the Ivanovka hospital.

Both caregivers and residents of these institutions understood that treatment in the psychiatric hospital was a form of punishment.

“[Ivanovka] was for those who behaved badly. They tied you down (to the bed), they did injections of Aminazin. I was there at least five times. It’s scary there, I didn’t want to go

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64 Human Rights Watch interviews with staff at Dmitrievka and Krasnaya Rechka residential special schools, Feb. 5, 2020.
65 Human Rights Watch interview with staff-member (name withheld) at Dmitrievka residential special special school, Feb. 5, 2020.
there,” said Aibek O., a 20-year-old who lived at Krasnaya Rechka school for children with intellectual disabilities from about 2005 to 2015.67

“For example [a boy in my care] was cursing, so they [school management] sent him to Ivanovka. We need to send all the children here to Ivanovka,” said one caretaker at Krasnaya Rechka residential special school. “The children don’t study while there. They come back calm, though it doesn’t last long. They come back sluggish and calm.”68

Some students said they avoided being sent for psychiatric treatment by showing good behavior. “They don’t send me to Ivanovka because I behave myself. I’m obedient,” said Alexei N., a 15-year-old boy who lived at Krasnaya Rechka school.69

**Lack of Consent for Treatment**

In all four of the institutions and special schools described above, staff said that children without parental guardians were medically treated, including with psychotropic medications, without their consent. Permission only needed to be granted by the institution director, who served as their legal guardian. Six young adults who formerly lived in residential institutions and special schools said they had either been given medication without their informed and free consent or had seen somebody else treated without consent. Katya N., a 20-year-old former resident who left the institution in 2017, said, “They gave us injections without any explanation why.”70

“We sent [a seven-year-old boy] there [to the psychiatric hospital], he behaves badly sometimes,” said one caretaker at Krasnaya Rechka residential special school. “He doesn’t have parents, so the director gave permission herself to send him to the hospital.”71

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68 Human Rights Watch interview with a caretaker (name withheld) at Krasnaya Rechka residential special school, Feb. 5, 2020.
70 Human Rights Watch interview with Katya N (pseudonym), in Belovodsk, Kyrgyzstan on Dec. 17, 2019
71 Human Rights Watch interview with a caretaker (name withheld) at Krasnaya Rechka residential special school, Feb. 5, 2020.
Some young adults said they suspected they had been treated with sleep-inducing medications as children in state care but could not be sure because staff never told them which medications they were getting. “I would get really sleepy and fall asleep sometimes after they gave us medicines. I asked the caretaker what she had given us, and she said vitamins,” said Bakyt K.\(^7^2\)

In the case of psychoneurological institutes, because parents relinquished guardianship upon giving a child over to the PNI, staff said there was no requirement to obtain consent for or inform them about their child’s medical treatment. The doctor at Jalalabad PNI said that only those parents who proactively took an interest in the child’s treatment were informed. “The parents find out about aggression and illness only if they want to, and when they visit,” said the doctor.\(^7^3\)

In residential special schools, where most children have a legal guardian outside the institution, staff said they had to obtain consent before sending the child to psychiatric treatment.

“We do it [send them to Ivanovka] if they hit each other or act nervously,” said Zamir Konokbaev, director of Dmitrievka School for Children with Intellectual Disabilities. “We propose it [to the parents] ourselves—we tell them they need treatment.”\(^7^4\)

However, it was unclear how informed parents were about the types of treatment available or potential outcomes or side effects. One staff member at the Dmitrievka residential special school showed Human Rights Watch a consent form that parents had to sign before their child would be sent for psychiatric treatment. These documents did not contain specifics about the type of treatment or medication that would be used in their children, and it appeared parents were informed of treatment methods only after they had taken place. It is unclear whether any efforts were made to engage children in discussions about the use of psychotropic medication in these cases.

\(^7^2\) Human Rights Watch interview with Bakyt K. in Murake on Dec. 17, 2019.
\(^7^3\) Human Rights Watch interview with a doctor (name withheld) in Jalalabad Psychoneurological Institute, Jan. 29, 2020.
\(^7^4\) Human Rights Watch interview with Zamir Konokbaev, director of Dmitrievka residential special school, Feb. 5, 2020.
According to Kyrgyzstan’s Law “On Psychiatric Help and Guarantees of the Rights of Citizens in Its Provision,” a child’s legal representatives, a parent or other guardian, must consent to medical treatment of the child. Before treatment, a doctor is “obligated to present... accessible information regarding the nature of his mental disorder [condition], the goals, methods, including alternatives, and duration of the recommended treatment, as well as potential risks, side effects, and expected results.” If the person being treated is a child, the parents or legal guardian must be given the above information.

While international law recognizes that children can be treated with consent of a parent or guardian, art. 12 of the CRC stresses the importance of children’s participation in this process. In its General Comment on the right of the child to health, the CRC Committee, which monitors states’ compliance with the convention, says that children’s views should be “seriously taken into account... on all aspects of health provisions, including, for example, what services are needed, [and] how and where they are best provided.”

A report by the Kyrgyzstan Ombudsman’s office found that in 2017, 54 percent of children admitted to psychiatric hospitals came from state institutions for children with disabilities. The report highlighted the “extremely vulnerable” position of children who were living in state institutions and were subject to psychiatric treatment, where “the conditions and absence of outside control increase the likelihood of rights violations.” The report found that “a majority of children are placed in [psychiatric] institutions “according to a decision by various administrative organs, and appeal is impossible.”

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Insufficient Safeguards Against Physical or Psychological Violence and Restraints

Children with disabilities in residential institutions and special schools in Kyrgyzstan have no true safeguards against physical or psychological violence. None of the institutions Human Rights Watch visited had accessible and confidential complaint mechanisms for children in place. In at least three institutions children were banned from contacting parents or guardians without staff supervision, and staff were dismissive of the need for confidential complaint mechanisms. It was difficult to speak openly about violence with children currently in institutions because in almost all cases, institution staff insisted that they either be present during an interview with the child or sat in the next room waiting for the interview to finish. These factors make it difficult to ascertain how any children might be affected by physical or psychological violence.

Despite these challenges, Human Rights Watch interviewed one girl currently in an institution and two former residents of institutions who said they had been subject to physical violence or restraints. “They beat me if I misbehave,” said the girl currently in an institution in Chuy region.79

Katya N., a 20-year-old who spent most of her life in institutions for children with disabilities but had been living independently in the community since 2017, said physical restraint was a common form of punishment in one of the institutions Human Rights Watch visited. “They tied our hands to beds, to doors. They tied you in [what we called] the ‘Letter A’ position,” she said, demonstrating by holding her hands behind her back.80

Violence is likely more common than the above cases indicate. The Kyrgyzstan ombudsman’s office published a report in 2017 on conditions in institutions and residential schools that documented how staff regularly committed physical, sexual, and psychological violence against children and that children also inflicted it upon other children.81 In 2014, the CRC Committee expressed concern about the “widespread abuse”

81 “Children were taken away from a woman and put into an institution. They were beaten there,” Kaktus Media, March 29, 2018, https://kaktus.media/doc/372304_y_jenshiny_zabrali_detey_i_pomestili_v_internat_a_tam_ih_izbili.html (accessed June 9, 2020).
of children in institutions and other settings, as well as the lack of complaint mechanisms and investigations into torture and ill-treatment of children in these institutions. In February 2020, the relative of a child in one institution visited by Human Rights Watch earlier that month accused staff of physical violence against the child. Law enforcement officials confirmed that the child had received bruises and said an investigation was ongoing.

Human Rights Watch is deeply concerned that no residential institutions or special schools visited had a confidential complaint mechanism for children with disabilities, creating a substantial risk that such abuses could occur with impunity. In at least three institutions, mobile phones were expressly banned and collected by caretakers or other staff for the duration of the child’s time in the institution. If a child wanted to use their phone to speak with their parents, they had to do so with staff supervision—one child said these calls were allowed no more frequently than every two to three days.

“They can call their parents only in front of the caretakers—they are ‘mentally delayed,’ they could say all sorts of things,” said the Zamir Konokbaev, director of the Dmitrievka school, using language frequently used to describe children with intellectual disabilities in Kyrgyzstan.

Institution or school staff appeared to brush off the need for complaint mechanisms, saying that there had been no problems with violence of any kind. “I have never seen

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85 Human Rights Watch interview with Bolot E. (pseudonym) at the Osh residential special school for blind children, Jan. 28 2020.
somebody harm a child [here],” said one school director who had been in her position for 11 years. 87

According to Kyrgyz law, no child can independently take any kind of legal action, either criminal or civil, against another person without the assistance of their legal representative. Their legal representative can be a parent, adopted parent, guardian, caregiver, or a representative of the organization responsible for caring for the child, such as institution staff. 88 The child has no say in who the court deems their legal representative, and the legal representative can only be removed from the case for a conflict of interest when the child is the perpetrator, not the victim, of abuse. 89

This creates a serious risk that children in institutions, whose guardians are either institution staff or parents who they might not be able to contact on a regular basis, have few defenses against potential abuse, or confidential avenues to report any abuse or neglect. This is particularly acute for children with disabilities, who may require accessible complaint mechanisms appropriate to their specific needs. According to the CRC, children have a right to be heard and taken seriously in proceedings “either directly, or through a representative or appropriate body.” 90 The CRC Committee has said that this body must exclusively represent the interest of the child and not the interest of any other person, institution, or body. 91

As a party to the Convention against Torture, the CRPD, and the CRC, Kyrgyzstan is obligated to protect children with disabilities from all forms of violence, torture, or

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inhumane or degrading treatment and should ensure that children enjoy safe and effective means of reporting mistreatment.  

The Code on Children of the Kyrgyz Republic states that “the state guarantees the integrity of the child and protects him from physical and (or) psychological violence, sexual violence, or cruel, rude, or degrading treatment.”

Denial of Education

Psychoneurological Institutes

In grave violations of their right to an education, children with disabilities living in psychoneurological institutes in Kyrgyzstan have no access to education and no formal schooling. In the two PNIs visited by Human Rights Watch, staff or volunteers organized small “classes” for the handful of children deemed fit by caretakers for some education. Those classes often consisted of teaching children basic skills such as recognition of numbers, letters, and colors. Staff noted that these children, at most 10 or 15 in total, were taught at a kindergarten or, in a handful of cases, third grade level, despite many being in their teens. Staff said that children entering these institutions were automatically deemed unfit for education. Only one child in the two institutions, which housed nearly 300 children, studied outside its perimeters: a boy with cerebral palsy who traveled to a private school every day.

“They are all diagnosed with ‘mental delay,’ and if they are ‘mentally delayed’ then they are automatically uneducable,” said an administrator at the Belovodsk PNI. “They can’t keep up with the [mainstream school] program. They are all ‘mentally delayed’ to some degree.”

All five former residents of PNIs Human Rights Watch interviewed said they had received virtually no schooling in these institutions and had no opportunity to attend mainstream or

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94 Human Rights Watch interview with an administrator (name withheld) at the Belovodsk Psychoneurological Institute, Feb. 4, 2020.
special schools outside of the institution. They were not taught to read or write, despite the fact that upon leaving the institution, or in some cases independently while in the institution, they learned to do so. The interviewees said only two or three hours a day were devoted to informal lessons, which were typically conducted by caretakers, not professional teachers.

“They would ask us stupid things like what color is red, things like that,” said Katya N., a 20-year-old in Chuy region.95

“There were no lessons, the caretaker just read fairytales to us,” said 22-year-old Malika K. “I wish they had taught me.”96

Substandard Education in Residential Special Schools

In Kyrgyzstan, nine years of schooling is compulsory, and children must complete 11 years of schooling to be eligible for university. The subjects covered and quantity of contact hours is determined by a national basic curriculum which is published every year.97 However, there is no single approved curriculum or quality standard for special education. Experts told Human Rights Watch that the curriculum taught in special schools was largely designed during Soviet times, though it had been supplemented by some administrative regulations since.98 NGOs have proposed implementing a “special state standard” that would allow educators to create individualized approaches for children with disabilities, which has received support from the Kyrgyz government but has not yet been implemented in schools.99 For now, however, teachers in residential special schools have little to guide their education of children with disabilities, particularly when it comes to creating individualized approaches for students with varying needs.

98 Human Rights Watch phone interview with Valentin Deichmen, Educational Program Director at Soros Foundation-Kyrgyzstan, June 23, 2020.
Parents of children with disabilities in residential special schools told Human Rights Watch that they felt their children were given little individual attention, particularly in cases when their level of study fell behind that of other students. In some cases, children appeared to be moved up different grades by teachers and school officials without clear proof offered to parents that they had learned sufficient skills and content to proceed.

“Those like [my daughter] just sit there, the teachers don’t work with them,” said Aida Mysalieva, mother of a 14-year-old girl, Adinai, who has an intellectual disability. Aida said Adinai’s ability to speak has not improved since she first enrolled in a residential special school eight years ago, and she remains unable to read, write, or master other basic skills. “They say they teach children practical skills, and there are some sewing machines there, but they teach only the good children [those who keep up with the school program],” she said.

“Special schools do not have individualized support for children,” said Seinep Dyikanbaeva, a disability rights activist and lawyer for the Parental Organization for Children with Disabilities (ARDI). “There is one program for everyone with different needs, the only difference is that it is less demanding than mainstream schools.”

In the Dmitrievka School for Children with Intellectual Disabilities, staff said that they graded all children as if they had passed the basic requirements of the school program, even if they had not. One teacher said, “We only give them a five or a three [out of five]. We can’t give them a two (a failing grade) because the Ministry banned us from doing that, so we give everybody threes,” said a teacher at the school.

In addition to the lack of quality standards, out of the four residential special schools visited by Human Rights Watch only one, the Osh School for Blind Children, offered a full 11th grade education to children and the rest offered only eight or nine years of schooling. After this, children received a “certificate,” rather than a diploma, accepted only at local technical schools, which follow a technical and vocational path. This meant that most children with disabilities in Kyrgyzstan are unable to access higher education at all.

102 Human Rights Watch interview with a teacher (name withheld) at the Dmitrievka residential special school, Feb. 5, 2020.
Tilegen, a 15-year-old boy who has cerebral palsy and is deaf, was unable to attend a mainstream school and so enrolled in a special school for the deaf in Bishkek. His mother, Ainura Aleeva, told Human Rights Watch that Tilegen has a serious interest in computers and wants to become a programmer, but she worries he will not be able to study programming at university because the school he attends now only teaches nine grades and issues one of the above-noted certificates, rather than a diploma. 103

Even among children who complete schooling at residential special schools, not all attend vocational schools afterwards. According to documents shown to Human Rights Watch by school staff, of the 15 children who graduated from Dmitrievka School for Children with Intellectual Disabilities in 2019, three were enrolled in the local vocational schools, and three were employed, while nine were neither working nor studying. 104 Some parents said this was in part due to the fact that vocational school opportunities were not extended to all children, particularly children with higher support needs.

Deprivation of Legal Capacity

According to Kyrgyz civil law, every person has the right to full legal capacity upon turning 18. 105 A person with a psychosocial disability can be deprived of their legal capacity by a court.” 106

During this process, a team of forensic psychiatric experts evaluates the individual and then presents evidence to the court. The person must be allowed to participate personally in the court proceedings, with few exceptions. 107 In these situations, “the case must be adjudicated at the location of the citizen and with his participation.” 108 The person has a right to appeal the decision or to petition for their legal capacity to be reinstated at any time. If a court deprives a person of legal capacity, the person will be appointed a

104 Documents shown to HRW by officials at Dmitrievka residential special school on Feb. 5, 2020.
106 Ibid., Art. 64.
108 Ibid., art. 294.3.
“guardian” who “is the representative of their ward before the law and carries out all transactions in their name and in their interest.”

Human Rights Watch found that upon turning 18, most young adults with disabilities living in psychoneurological institutes for children are either transferred automatically to an adult institution or sent to live with parents or other relatives. Activists and experts whom Human Rights Watch interviewed could not specify how young adults with disabilities were deprived of their legal capacity and placed under guardianship of the adult institution or relatives. Institution administrators confirmed that all decisions regarding legal capacity and guardianship were made by a court, but they could not specify who initiated the court proceedings, whether the individuals were allowed to take part, and, if they did not participate, who represented them in these proceedings.

Amnesty International documented how in 2017, 67 residents of one adult institution were deprived of their legal capacity in a single day. Such figures strongly suggest that many, if not all of these, individuals were denied participation in court proceedings concerning them.

“When they turn 18, they are [declared] incompetent [by a court]. In order to live independently they need to have the court declare them [legally] competent. In my time, there haven’t been any such cases,” said an administrator at Belovodsk Psychoneurological Institute who had worked there for over 10 years. Asked, for example, about one girl with a physical disability who would most likely be sent to an adult institution, they said, “She can’t manage alone, so in any case the court would decide that she can’t live alone.”

According to 2018 statistics that staff of the Jalalabad Psychoneurological Institute showed Human Rights Watch, of the 15 residents who had left the institution, 12 were transferred to adult institutions that assumed guardianship over them. In Belovodsk Psychoneurological Institute, of 44 children who left in 2018, 22 were transferred to adult

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109 Civil Code of the Kyrgyz Republic No. 15, Art. 67.
112 An additional two people registered as “leaving” the institution in 2018 died.
institutions who assumed guardianship over them, seven died, and the remainder returned home to their families. Even in cases where a child was sent home, institution staff said guardianship was transferred to parents, giving them control over where a person with a disability lived, whether or not they worked, and control over their finances. “We don’t follow up on what happens to them after [they go home to parents],” said the above administrator.113

Even when young people with disabilities leave an institution, courts may not always mandate or encourage their participation in cases regarding their legal capacity. Gulbarchyn Takyrbasheva, the director of Social Village Manas, a nonprofit group that supports young adults with disabilities to transfer out of state institutions and become professionally independent, said that when she has petitioned courts to overturn the decision that deprived young adults of their legal capacity, the court requires the young person’s participation in a psychiatric examination but does not encourage their participation in the court hearings.114 However, she said that her organization had successfully supported some young people to petition to have the decision to deprive them of legal capacity fully or partially overturned.

Four young adults who lived at accommodation provided by Manas Children’s Village said if the group had not helped them, they would have been automatically transferred to an adult institution.115

“There’s a big difference between here and an [adult] institution,” said Ruslan P., a 24-year-old with a speech disability. “Here you can be independent and thank God I am able to work. If I had gone [to the adult institution] I would have died.”116

Children with disabilities in institutions either seemed unaware of where they would live after reaching adulthood or expressed fear about what would happen. “That’s scary—it’s better not to even think about that,” said one 17-year-old.117

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117 Human Rights interview with a resident (name withheld) of the Belovodsk Psychoneurological Institute, Feb. 4, 2020.
Under international human rights law, every person has a right to recognition as a person under the law. The CRPD further emphasizes the right to exercise legal capacity. Children with disabilities are particularly vulnerable to being denied the choice to leave institutions upon reaching adulthood, and states should fully respect their right to full exercise of legal capacity.

Art. 12 of the CRPD establishes the assumption that persons with disabilities can act in their own best interests and that, when needed, they should be given support to do so. This assisted decision-making system should be a regime of support for the individual’s exercise of rights, a process by which the will and preferences of the person are fully respected. This system should contain safeguards ensuring that the support provided is proportionate to the person’s circumstances, limited in duration, free from conflicts of interest, and subject to regular, impartial review by a judicial body.
III. Barriers to Children with Disabilities in the Community and Consequences for Deinstitutionalization

Many factors lead to children being placed in institutions, including poverty, migration, and lack of services. But barriers to quality and inclusive education create particular hardship for parents of children with disabilities and may facilitate placement of their child in a residential institution or school.

Human Rights Watch interviewed four children with disabilities and 27 parents of children with disabilities in an effort to document these barriers. In many cases, children were discriminated against during enrollment, denied the right to attend school, and offered home education instead. In other cases where a child did manage to access mainstream schooling, they faced barriers once there, including physical inaccessibility and lack of a reasonable accommodation, meaning a modification or adjustment that would allow them to fully enjoy their rights on an equal basis with others.\(^{121}\)

The CRPD requires states to ensure the right of persons with disabilities to education through an inclusive education system at all levels.\(^{122}\) Inclusive education involves “the full and effective participation, accessibility, attendance, and achievement of all students, especially those who, for different reasons, are excluded or at risk of being marginalized.” To achieve this, states must ensure “accessible learning environments with appropriate supports. The education system must provide a personalized educational response, rather than expecting the student to fit the system.”\(^{123}\)

Inclusive education stands in sharp contrast to the special education model, in which children with disabilities are taught in segregated schools outside the mainstream, in special programs and institutions and with special teachers. In this system, children with and without disabilities have very little interaction, which can lead to greater marginalization within the community, further entrenching discrimination of people with

\(^{121}\) CRPD art. 2.


disabilities. Research shows that an inclusive approach can boost learning for all students and combat harmful stereotypes of people with disabilities.124

Efforts to end institutionalization of children are notable. But unless the Kyrgyz government takes serious steps toward implementing quality inclusive education, current barriers for children with disabilities create the risk that they will continue to be placed in environments that are ill-equipped to serve their educational needs and to face barriers to enrollment in mainstream schools.

The Revolving Door of Institutionalization

Residential institutions and special schools still serve as a mechanism for delivering social services to families who are experiencing difficult life circumstances, including poverty, lack of employment, and illness. And even while parents often deemed the education and services available to their children at residential special schools substandard, many also implied that their child was more likely to access specialized teaching and support there than in a mainstream school.

This was particularly true for deaf and blind children. Parents, children, and experts told Human Rights Watch that braille and sign language were almost exclusively taught in residential special schools for blind or deaf children, and other aids, for example, large-print text books, were similarly only provided in such settings.125

Ainura Aleeva, the mother of 15-year-old Tilegen who studies in a special school for the deaf, said there was no other option for her son because sign language was not taught in any non-specialized schools. “We had no choice [but to study in the special school]. If he studied in a normal school he would need a special teacher [who knows sign language],” she said.126


All four children with visual disabilities Human Rights Watch interviewed at Osh School for the Blind said they were not taught braille and did not have any access to large-print or otherwise adapted textbooks and educational materials before attending the school. 127

Parents whose children had intellectual disabilities similarly expressed hopelessness at the idea of enrolling their child in a mainstream school, concerned that the school would not provide their children any reasonable accommodations, or that their children would be ignored by teachers inexperienced and untrained to teach children with disabilities.

“I know what mainstream schools are like, there are 40 students in one class, they [the teachers] wouldn’t have time so much as to glance at him,” said Elena, the mother of Danya, a 15-year-old boy with Down’s Syndrome. Without access to the residential special school he attends, she said, “He would most likely just sit at home.” 128

“In Kyrgyzstan, there is no interconnection right now between mainstream and special schools, they don’t interact with one another,” said Rakhat Orozova, an independent expert on inclusive education. “First we need to create conditions for the teaching of children in mainstream schools, and then we can undertake deinstitutionalization.” 129

Human Rights Watch interviewed four parents who had taken their children out of residential special schools in the last year, most of whose children experienced barriers to inclusive and quality education upon enrolling or attempting to enroll in community schools. 130

One girl had successfully enrolled in a mainstream school, but the school requested that she leave after she began exhibiting behavior the staff at school found “difficult,” and she had been at home without schooling for several months. 131 In a second case, a boy with an intellectual disability successfully enrolled in a mainstream school, but his mother said

that staff failed to engage him in the classroom and did not give him homework.\textsuperscript{132} A third family said their daughter had flourished since enrolling in a mainstream school.\textsuperscript{133} The fourth family said they had made no efforts to enroll their daughter in a mainstream school because they were convinced she would not be accepted.\textsuperscript{134}

These stories are not fully representative of those taking part in the deinstitutionalization program. Human Rights Watch had difficulty in obtaining complete and up-to-date contact information for families participating in the program, despite requests to the Ministry of Education and participating nonprofit organizations. However, the diversity of these experiences speaks not only to the importance of consistent support to families who have been reunited with their children after they have lived in institutions, but the difficulties many children with disabilities have when attempting to access education in their communities. It is clear that for deinstitutionalization to truly succeed, families taking their children out of institutions, and all families of children with disabilities, must be better supported in accessing quality education in their communities.

**Physical and Other Barriers in Mainstream Schools**

Children with disabilities living in their communities who have attempted to enroll in and attend mainstream schools face many barriers, including inaccessible physical infrastructure, inadequate assistance, such as absence of large-print or adapted textbooks, or braille for children who are blind or have low vision, and lack of staff qualified to teach children with disabilities, particularly intellectual disabilities.

Of the 27 children whose families were interviewed by Human Rights Watch, five studied full or part-time at mainstream schools with infrastructure that they or their parents said required a relative to be physically present for much of the school day in order to facilitate the child’s learning. Some interviewees said their schools lacked entry ramps, while others lacked ramps or elevators to classrooms on the second or third floor, and in some cases toilets were inaccessible. Parents, who then became responsible for physically carrying their child into school or the classroom, said they had to sacrifice employment or arrange their schedules to accommodate these barriers.

\textsuperscript{132} Human Rights Watch phone interview with Hajar Islamova on March 18, 2020.
\textsuperscript{133} Human Rights Watch phone interview with Ibadat Zhanysheva, March 18, 2020.
\textsuperscript{134} Human Rights Watch phone interview with Uulkan Erkebaeva on Feb. 17, 2020.
Eleven-year-old Ruslan Musabaev, who has cerebral palsy, told Human Rights Watch that the mainstream school where he is enrolled has an entry ramp to the building but does not have a ramp to the third floor, where he studies. His adopted mother attends school every day and helps him climb the stairs and go to the bathroom, which is also inaccessible, waiting downstairs in the cafeteria in case he needs her assistance.135

Two former residents of psychoneurological institutes who used wheelchairs said that lack of physical accessibility had been the main reason they weren’t able to attend school. Asel N., a 25-year old woman who uses a wheelchair, was able to attend a mainstream primary school because her father carried her and her wheelchair into the school every day—both her school and the building in which she lived lacked an accessible ramp. When she was nine, he died. Without anybody else in the family to perform this task, they decided to send Asel to an institution.136

Three children who are blind or have other visual disabilities at the Osh Residential School for Blind Children said they had transferred to the special school after struggling to study in mainstream schools, primarily because they were unable to see the board and because the school did not provide them reasonable accommodations beyond seating them at the front of the class.

Amantur Zhusupov, a 13-year-old boy with cerebral palsy and a visual disability who is currently enrolled in a mainstream school in Osh, needs his mother to attend school full-time with him so she can dictate what is written on the board. His mom told Human Rights Watch, “It has a negative impact on me, I have had to abandon many things and I leave my other daughter alone... I sacrifice myself and we live on benefits.”137

Human Rights Watch interviewed parents of three children with intellectual disabilities who were admitted to mainstream schools, but whose children struggled because schools failed to provide them any reasonable accommodations, such as a modified curriculum or an aide to support their learning in the classroom. The parents of all three children told

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Human Rights Watch that teachers did not appear willing to educate their children, instead giving them a “free pass” on assignments, homework, and grades.

“The education in the residential special school was better, they gave him homework, but here [in the mainstream school] there’s nothing like that... They give him threes (a passing grade),” said Hajar Islamova, the mother of a boy with an intellectual disability. 138 “At home I work with him, just so that he won’t forget how to read or write.”

**Discrimination in Enrollment**

*MSCE and PMPC: An Introduction*

Kyrgyzstan has two state bodies tasked with evaluating children with disabilities. The Medico-Social Commission of Experts (MSCE), which falls under the Ministry of Labor and Social Development (MLSD), and the Psycho-Medico-Pedagogical Consultation (PMPC), which falls under the Ministry of Education and Science.

Upon reaching school or pre-school age, children with disabilities are expected to undergo an examination by the PMPC, which includes medical experts as well as a psychologist, speech therapist, and pedagogical experts. 139 The PMPC’s role is to examine a child and issue a recommendation regarding a child’s educational path. The PMPC evaluation is formally a recommendation only, and ultimately must be made “with the agreement of the parents of the child.” 140 The PMPC can recommend that a child attend a residential or non-residential special school, or recommend medical treatment or rehabilitation for children “not able to learn in schools... due to their health or intellect.” 141

The PMPC has created specific guidance ruling on a variety of cases, including in cases when a child’s parents seek to enroll them in a mainstream school. 142 The guidance

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139 Human Rights Watch phone interview with Tatiana Romanova, director of Republican PMPC, April 21, 2020.
142 PMPC, “Informational and methodological manual on the work of the Psychological-medical-pedagogical consultation: To help professionals and parents about access to education for children with disabilities,” 2016 [In possession of Human Rights Watch]; Ministry of Health and Ministry of Education and Sciences of the Kyrgyz Republic, Instructions “On the intake
restricts access to mainstream schools to children with specific disabilities. Some of those who are recommended to mainstream schools are only allowed to be placed in segregated so-called “correctional classrooms.”

Defining some children as “not able to learn” and limiting recommendations for access to mainstream schools to children with certain types of disabilities is a violation of Kyrgyz national law on the right to education as well as Kyrgyzstan’s international obligations to guarantee quality, inclusive education. The government should abolish the PMPC, given its decisions are often used formally or informally to deny children access to inclusive education. Funds should be redirected to schools or school districts to create dedicated professional teams to identify the reasonable accommodations necessary to meet individual requirements. These teams should invite the student and their parents or guardians to participate and share information about the child to determine the necessary accommodations. These teams should conduct an assessment, with a view to outlining an individual learning plan or education program which would be reviewed on a regular basis and accommodations adjusted as necessary.

There are only two PMPCs that assess children year-round in Kyrgyzstan, both of which are in the capital of Bishkek. The remaining 18 PMPCs all over Kyrgyzstan convene only once or twice a year, typically for one day. Tatiana Romanova, director of the Republican PMPC in Bishkek, estimated that between 1,200 and 1,500 children are assessed by the Republican PMPC each year, but that each regional commission assesses around 80 children. Because of this, only eight out of 36 parents interviewed for this report told Human Rights Watch that their children had undergone the examination, almost all of them in the capital of Bishkek or nearby towns, whereas in more remote parts of the country parents said they had never been told about the PMPC. This lack of capacity further underscores the need for an alternative system to facilitate access to education for children with disabilities.

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\(^{143}\) Ministry of Health and Ministry of Education and Sciences of the Kyrgyz Republic, Instructions “On the intake of children with disabilities into general educational schools, preschools, working on the basis of inclusive education,” July 10, 2008. [In possession of Human Rights Watch]

\(^{144}\) Human Rights Watch phone interview with Tatiana Romanova, Director of the Republican PMPC, April 21, 2020.

\(^{145}\) Ibid.
In addition to the PMPC, children with disabilities are also typically assessed by the MSCE. Unlike the PMPC, this assessment can take place at any age and the decisions rendered can be reviewed at intervals of one, two, or five years. The primary role of the MSCE is to determine whether a person has a disability, to assign them to a “disability group” (categories based on the so-called functionality of a person and their ability to independently perform tasks of daily living), create an individual rehabilitation plan for their medical treatment, and to facilitate their receipt of assistive devices and social support.

There are 28 MSCE offices around the country, located in medical facilities or in local government buildings. The national director of the MSCE, Zhanyl Akbaeva, told Human Rights Watch that local units are equipped with cars in order to conduct home visits, which she estimated make up about 60 percent of MSCE consultations. The MSCE is comprised exclusively of medical professionals, and according to parents of children with disabilities, the assessment consists primarily of physical and medical examinations.

Because of its widespread accessibility and because the MSCE assessment is also used to determine whether an adult or child is eligible for disability payments, all parents interviewed by Human Rights Watch said their child had been evaluated by the MSCE. The MSCE also conducts an evaluation of a child’s so-called “capacity for study” and can rule a child “capable of learning,” “capable of learning only in a special, or correctional, educational facility,” or “not capable of learning.”

Akbaeva told Human Rights Watch that these assessments are meant to serve only as guidance that can then be used by the PMPC to make a final recommendation about a child’s educational path. However, she acknowledged that in places where the PMPC lacked capacity, schools sometimes do use the MSCE evaluation to deny children enrollment, though she said that was not its intended use. Outside of Bishkek and Osh, Human Rights Watch found that the MSCE played a significant role in a child’s ability to enroll in a mainstream school.

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The government should clearly establish in law that an MSCE evaluation can no longer categorize children for supposed “capacity to learn” and should not be used to determine a child’s access to education. No child should be declared incapable of learning or deemed only qualified for special education or home education. These types of categorizations are discriminatory and contrary to Kyrgyz law and Kyrgyzstan’s international legal obligations and should be eliminated. Instead, state agencies should identify and supply the supports, or reasonable accommodations, a child needs to attend school and receive a quality inclusive education.

**MSCE and PMPC As Obstacles to Enrollment**

While neither MSCE nor PMPC decisions regarding a child’s education are legally binding or mandatory, many parents said that, in the absence of alternative information, they felt compelled to follow their recommendations, often leading to their child’s segregation.

When her daughter Adinai was five, Aida Mysalieva began noticing that she was unable to string together complete sentences like other children her age. The family doctor referred Mysalieva to the PMPC. Mysalieva wanted her daughter to attend a mainstream school, “I thought that with time, she would speak.” But the PMPC determined that Adinai was “mentally delayed,” a term widely used to describe children with intellectual disabilities in Kyrgyzstan, and that she should study at a residential special school for children with similar diagnoses. “[The PMPC] said she won’t be like [us], she won’t be like other children.”

Two years later, frustrated that her daughter was still unable to speak, Mysalieva appealed to the PMPC again. She begged them to reexamine her daughter and, if they couldn’t give her approval to enroll in a mainstream school, to at least transfer her to a residential special school for children with speech disabilities, where she might be allotted more time with a speech therapist. “They said she couldn’t study there because she is diagnosed with an intellectual disability,” she said. “I cried.” Adinai, now 14, still does not speak, a problem her mother in part attributes to the lack of regular speech therapy at school.

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149 Human Rights Watch interview with Aida Mysalieva in Bishkek, Kyrgyzstan, Feb. 3, 2020
150 Ibid.
Experts and nonprofit organizations told Human Rights Watch that the PMPC was a conveyer belt into special schools, particularly in the case of residential special schools, where the PMPC assessment was often conducted on special school grounds and by school staff who had an added incentive to boost class numbers.

“At this time, the PMPC sends all children to special schools,” said Larisa Kuznetsova, director of Smile.KG, an organization that works with children with intellectual disabilities. “The PMPC is conducted in August when the children are entering first grade, and it often operates within a residential special school. These are children who have already been accepted into the school. The exams are a formality and there is no genuine assessment.” ¹⁵¹

In the Uch-Korgon Residential Special School for Children with Intellectual Disabilities, the PMPC was housed in the school itself and made up of school staff. Forty-nine of 149 children seen by this PMPC were enrolled in the school in 2019. Through interviewees, Human Rights Watch learned that at least two children were studying there only because their siblings were enrolled in the school. Nurbek M., a 13-year-old boy, said he was only studying there “to look after [my] little brother,” who he said had an intellectual disability. ¹⁵²

The director of one NGO for child protection described one residential special school where over 80 percent of the children shared a single diagnosis of “light mental delay.” Upon investigating the children’s files, the text of each PMPC document had been copied from one another. ¹⁵³

In more remote parts of the country, parents of children with disabilities had never heard of the PMPC, or if they had, said it was too far away to access. In Barpy, a village near the city of Jalalabad, six out of nine caretakers of children with disabilities said their children had been excluded from mainstream schools, or allowed to enroll and then their enrollment was terminated, because an evaluation by the MSCE deemed them fit only for home education.

“I only heard of the PMPC for the first time last year. They have no staff in our area so everybody goes to the MSCE,” said Nurzhamal Shabdanova, the director of a day center for children with disabilities in Barpy called Ene Meerimi (“Mother’s Love”), and also the grandmother of a boy with cerebral palsy. “Most schools ask for a reference from a doctor and the decision from the MSCE [before enrolling a child with a disability].”

**Lack of Information for Families with Children with Disabilities**

Parents of children with disabilities told Human Rights Watch that the PMPC, MSCE, and other state bodies have failed to give them adequate information about their child’s right to an inclusive education. As a result, only parents able to easily access alternative information and support from a nonprofit organization or members of their community were made aware of their child’s rights and were able to successfully oppose discriminatory efforts of school directors or staff and access inclusive education for their children.

Gulmira Mamatisaeva has two children with cerebral palsy. Previously, she was unaware that children with disabilities had a right to education, and so never made an effort to enroll her older daughter in school. When her younger son, Artur, was born in 2007, however, “I began to learn about rights,” she said, thanks to help from the NGO Smile.KG in Osh.

“The director [of the school] didn’t want [to let him in], but I insisted on my rights,” she said. “If I hadn’t known the law and didn’t insist, they wouldn’t have accepted him. Many [parents] don’t know.”

Tamara Balkibekova, head of Child’s Dream, an NGO that supports families of children with disabilities in a village near Bishkek, said of the process of enrolling those children in schools, “We include them by force.” “There is no attention [from schools]—we insist we have a right to education, and that’s the only reason they accept us.”

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156 Ibid.
When Kanatbek, an 18-year-old with cerebral palsy, attempted to enroll in school the PMPC determined that he should study in remedial classes held within a mainstream school but separate from other students. When these classes ended in the fifth grade, his mother, Nazgul Abdyzhaparova, appealed to the PMPC again in the hopes that Kanatbek would now be able to enroll in a regular classroom in a mainstream school. Instead, the PMPC said he should receive education at home.¹⁵⁸

“I had been sure they would take him. He read a lot. He had the strength for it. But they tested him very superficially,” she said. The family was disappointed by the PMPC’s assessment that relegated him to home education. “We knew that they [the teachers] wouldn't actually come to him [at home], and we would have to do everything ourselves.”¹⁵⁹

But Abdyzhaparova said Kanatbek was determined to study in a mainstream school. As he was growing up, she had joined parent groups online and offline and learned more about her son’s right to an education. Ultimately, she convinced the administration of a local school to enroll her son, though at first, they expressed reluctance about admitting a child with a disability without a corresponding PMPC evaluation recommending enrollment. Abdyzhaparova said Kanatbek’s success in enrolling was possible partly due to the family’s comfortable financial situation, which allowed them to invest in his education, speech therapy, and expensive medical treatments.

“I give the government two points out of five. We didn't get any help... If you have the material support, you can manage—if not you can’t,” she said.

However, in cases where families of children with disabilities had fewer material or informational resources, parents felt they had little choice but to accept the decision of the PMPC or school staff. For example, Mysalieva, mentioned in the section above, did not feel she had the right to ask about alternatives when the PMPC denied her request to transfer her daughter to a different special school or to a mainstream school. “We don’t give

¹⁵⁹ Ibid.
anything [any money]. I am ashamed to demand [things],” she said. “I’m just grateful that they look after her for a week, otherwise where would I leave her?”  

*Lack of Inclusion or Accommodation in Mainstream Schools*

Even when families insisted on their child’s right to an education and were ultimately allowed to enroll full or part-time in a mainstream school, their attendance there was often insecure and subject to arbitrary termination. Parents said some school directors implied that enrolling children contrary to a recommendation by the MSCE or PMPC was a violation of the rules, and otherwise made it clear that they were making an exemption and doing a favor by allowing a child to attend.

Dzhimakan Sultanova, mother of eight-year-old Syrgak, was delighted when after one year of education at home, the director of a local school allowed her son to attend the equivalent of a kindergarten class. However, Syrgak, who has autism and difficulty speaking, had only been attending for a few months when another child with a disability was expelled from the school for behavior the staff considered unacceptable. Staff told Sultanova that Syrgak also could no longer study there, saying he did not have the appropriate documentation from the MSCE greenlighting him for study in a mainstream school.

“His teacher said if there was an inspection [by the authorities] it would be proven that he didn’t have the proper documents to study there,” said Sultanova. He had been at home for several months, which had proven difficult for him. “[Syrgak] doesn’t want to be at home, he wants to be at school,” she said.

Others said they limited their attendance so as not to risk termination of their child’s education.

The PMPC determined that Adilet, who has cerebral palsy and is now nine, was only eligible for home education. His mother, Aizada Mamykeeva, approached the director of a

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162 Ibid.
school in their village of Leninskoe, 15 kilometers outside of the capital of Bishkek, to ask if he could nonetheless attend.

“[The director] said people will be scared, the other children will be scared, [so] stay at home [and] we’ll allocate you a teacher (for homeschooling),” she said. Thanks to the NGO Child’s Dream, they were able to enroll Adilet part-time in school. “If I had gone by myself and she had said that [we don’t have a right to enroll], I would have left right away, I didn’t know anything,” she said.163

However, due to the director’s resistance, Aizada says she limits her son’s attendance to a few classes per week, so as not to draw too much attention to her son and risk having him removed from the school.

“The director was opposed, and she very reluctantly agreed. That’s why we don’t go often, so as not to create problems,” she said.164

In addition to the barriers posed by the MSCE and PMPC, children also faced discrimination by officials in mainstream schools who are reluctant or refuse to admit children with disabilities. The reasons given by officials varied, ranging from the misconception that these children’s appearance or behaviors would frighten their classmates without disabilities or that the children with disabilities would be unsafe attending those schools.

Kenzhekan Isabekova’s now 15-year-old daughter has a visual and an intellectual disability. She had no difficulties enrolling her at a mainstream school at first, but teachers reacted negatively when her daughter had difficulties keeping up with the curriculum. “She wasn’t interested, they didn’t pay any attention to her, she just sat there and played,” she said.165 Ultimately, teachers asked her to take her daughter out of school. With no other options available, Kenzhekan’s daughter now attends school in a residential special school for children with disabilities.

164 Human Rights Watch interview with Aizada Mamykeeva in Leninskoe, Kyrgyzstan, Feb. 6, 2020
Nurzhamal Shabdanova’s 10-year-old grandson Nurislam, who has cerebral palsy, was initially admitted to a mainstream school. But within a month, her teacher asked them to stop attending school and accept education at home instead. “The other teachers told her she would be responsible if anything were to happen to him,” said Shabdanova.\(^\text{166}\)

One mother said the staff rejected her child with an intellectual disability, Bektemir, when he turned seven years old because the MSCE ruled him only fit for education at home, which he has received ever since. “They said there were four children like him in the area, and if they let him in, they would all come [to the school],” she said.\(^\text{167}\)

**Shortcomings of Home Education**

Children with disabilities often receive home education, typically because a MSCE or PMPC decision effectively excludes them from attending mainstream schools or because the special schools which would accept them are too far away or difficult to enroll in. Children who receive home education are formally enrolled at a mainstream school, and the school allocates a teacher to come to their home several times a week. However, the children do not receive an education in the school together with their peers, and while in a minority of cases families made arrangements with school staff to attend certain classes such as gym, most never attended the school at all.

In 2018, Kyrgyzstan adopted a policy statement “On the Organization of Individual Education of Children at Home,” which states that the “goal of organizing individual education for children at home is defending their right to receive an education.”\(^\text{168}\) At the time of the policy’s adoption, 474 children in Kyrgyzstan were receiving home education.\(^\text{169}\)

According to the policy, children with a disability can receive home education if they present a PMPC decision or information from a medical body detailing a health problem to the school. The individual educational program for each child should be based on the

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Essential Educational Plan, which outlines basic requirements for the curricula of mainstream schools, including a minimum of 20 to 30 schooling hours per week. According to the policy, children receiving home education should get no less than half the number of contact hours as children in school: 10-12 hours compared to those receiving 20 hours of in-school contact, for example. 170

Despite this, children with disabilities interviewed by Human Rights Watch received as little as one-and-a-half hours of education at home per week to a maximum of four-and-a-half hours per week. Parents said that most teachers had no specific training or experience working with children with disabilities, and that they limited their teaching hours. In some cases, teachers said they believed children with disabilities were easily exhausted by academic exertion.

Aidana Mamatova, mother of Omurbek, an 11-year-old boy with cerebral palsy, said that when her son first began home education in first grade, the teacher came once a day. Now, she only visits for 30 minutes, three times per week. “[The teacher] says, ‘He won’t manage longer than that.’... She says that half an hour is enough for these kinds of children,” she said. 171 Mamatova says that while Omurbek has been enrolled in homeschooling for four years, he is not at a fourth-grade level. He recognizes individual letters but cannot read, and can only add up to 10.

Aida Abdykalby Kyzyy, the mother of a nine-year-old boy with cerebral palsy, said that a teacher came to study with him for three hours each week. She said that while the teacher got along well with her son and played with him, the program was nothing like real school, which she wanted for her son. “It’s a simplified program. They read fairytales, learn letters and numbers, sing songs,” she said. 172

Children who receive education at home should, according to government policy, have an individual plan adapted to their needs and undergo a performance assessment each quarter in the presence of a teacher. These results should then be used by a school board

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to determine whether the child can move up a grade. However, none of the parents who spoke to Human Rights Watch said their child had been assessed for educational attainment.

“Home education is the easiest means of getting rid of children [with disabilities], if the PMPC decides they are incapable of receiving education [in a school] they send them for home education,” said Rakhat Orozova, an independent expert on inclusive education.

“An individualized program doesn’t mean the child should study at home, it implies they should be able to go to some classes and maybe do others at home. But instead [according to government policy] individual education has come to mean home education.”

Sometimes, parents had to forego education at home because teachers were only able to conduct lessons at times when the parents were working. Orozali Sulaimanov, whose 11-year-old son Sayan was asked to leave school because he has speech and intellectual disabilities, asks a school-age relative to give Sayan ‘lessons’ because both he and his wife work full-time. “She comes when it’s convenient for us, whereas a teacher wouldn’t do that,” she said.

Home education denies children the right to inclusive education. It segregates and isolates children with disabilities from their peers and community, depriving them of socialization. Children with disabilities repeatedly expressed positive experiences from attending schools and interacting with other children, and parents of children with disabilities said their children suffered from lack of socialization when barred from school. They are deprived of the chance to play with other children and to form friendships. Forming bonds and socializing with children their own age is important for the child’s developmental health and development of social skills. Parents of children with disabilities also told Human Rights Watch that their children lost motivation while receiving education at home compared to when they had attended school, as the company of other children stimulated their learning.

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When 11-year-old Sayan was removed from school, Sulaimanov said, “It had a negative effect on him. When he went to school, he learned poems, he liked it there. [When he left,] he would bring school clothes every day to us and we had to explain to him that he wasn’t going anymore.”  

Nurzhamal Shabdanova, whose grandson attended school until school officials asked him to leave, said, “When he studied with other children it was better, he remembered things better, maybe because of [the influence of] his friends... At home these children are isolated, they’re all alone.”

Under international standards home education should be temporary. As the UN special rapporteur on the rights of persons with disabilities concluded in neighboring Kazakhstan in September 2017, “home schooling should be an exceptional and temporary measure for children whose health does not allow them to attend school, rather than a practice to further segregate children with disabilities.”

Kyrgyz government policy dictates that a decision to recommend home education for a child should be reviewed at least once a year, presumably in an effort to prevent this situation from becoming permanent. However, families in most cases said children had been receiving home education since they turned school age, in some cases more than four years, underscoring that home education is not in fact an exceptional or temporary measure for some children with disabilities in Kyrgyzstan.

**Complete Lack of Education for Some Children**

While there are an estimated 30,000 children with disabilities in Kyrgyzstan, according to Ministry of Education statistics shared with UNICEF, only 10,925 are registered as receiving education of any kind. Human Rights Watch documented three cases in which children or young adults had not received any education at all. Parents were unaware of their right to access education for their child or how to go about it, unable to pay for transport costs.

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176 Ibid.
to the nearest special school or to make the journey to these schools on a regular basis, or preemptively made the decision not to enroll their child in school out of an expectation that the child would be excluded or discriminated against. Experts interviewed by Human Rights Watch confirmed these obstacles and also cited difficulties accessing the PMPC as a barrier to enrollment for some children.  

Primary and some secondary education is compulsory in Kyrgyzstan. All children should be in school by six or seven years old. Children must complete at least nine grades of schooling, at which point they can enter the workplace, or continue their technical or professional education. International human rights law makes clear that all children have a right to free, compulsory, inclusive primary education, free from discrimination.

Human Rights Watch interviewed one 28-year-old woman with a disability who had had no access to schooling. She had a physical disability that made it impossible for her to access school transportation, and her parents preferred she stay at home with her sister, who was a wheelchair user. She described how her inability to receive an education had led her to feeling isolated as a child and undermined her long-term career prospects:

“I regret it [not going to school]. If my parents had sent me then [to school], I would have finished my studies. I would have had friends other than my neighbors. I would have studied at university and continued my education.”


Ministry of Education and Sciences of the Kyrgyz Republic, “The System of Education,” https://edu.gov.kg/ru/about/sistema-obrazovaniya/#:~:text=%D0%9F%D1%80%D0%BE%D0%B4%D0%BE%D0%BB%D0%B6%D0%B8%D1%82%D0%B5%D0%BB%D1%8C%D0%BD%D0%B8%D1%8F%20%D0%BB%D1%8E%D0%BB%20%D1%83%20%D1%89%20%D0%BD%20%D1%83%20%D0%BE%20%D0%BB%20%D0%BE%20%D1%81%82%20%D1%8C%20%D0%BE%20%B1%83%20%7D%05%0BD%0%8B%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0%82%20%7D%05%0D%0 (accessed June 5, 2020).


Jazgul, a 15-year-old girl with Down’s Syndrome, has never been to school or received any formal education. Her mother, Bayasha Janybaeva, said, “I heard about other friends who had children with disabilities, and they were removed from school.” She said she had wanted to send Jazgul to a special school for children with Down’s Syndrome but the nearest one was in Osh, a one-and-a-half-hour drive away, and she couldn’t afford the journeys. Jazgul primarily spent her time looking after Janybaeva’s three young grandchildren, who were living with her while their parents were abroad for work.185

Uulkan Erkebaeva took her nine-year-old daughter, Sezimay, out of a residential special school for children with disabilities when the family moved away from Bishkek to a remote part of the country. The only option for schooling there is a mainstream school where her daughter would most likely not receive reasonable accommodations for her disability. While Sezimay did receive an education in the special school, upon leaving in the fall she had received no schooling.

“When we go into the street people look at her, and at school it would be even worse,” said Erkebaeva. “She’s different from other children, they’ll point their finger at her. She can’t sit normally, she’s constantly moving or walking.”186

Erkebaeva said that there had been no follow-up from social services since taking her daughter out of the institution. “Nobody has come to us or explained anything [to] us,” she said. “They haven’t monitored whether she’s going to school or not.”187 Erkebaeva said the family was contemplating sending Sezimay back to the special residential school.

Chynara Kumenova, an education specialist at UNICEF, noted additional obstacles parents of children with disabilities have reported. “The PMPC is not accessible [geographically] to many parents. If a child is referred to a special school, they are often full, and parents need to give an informal bribe, which many parents cannot afford,” said Kumenova. “If [parents] take the child to mainstream schools, they are advised [by school staff] that they will not be able to work because they will need to stay with their child at all times.”188

187 Ibid.
188 Human Rights Watch phone interview with Chynara Kumenova, July 1, 2020.
IV. International and National Legal Standards

In March 2019, Kyrgyzstan took the important step of ratifying the CRPD, which came into force in Kyrgyzstan on May 16, 2019. In addition, Kyrgyzstan has been a party to the CRC since 1994.\textsuperscript{189}

International Standards

Quality, Inclusive Education

The CRPD obligates states to ensure that persons with disabilities “can access an inclusive, quality, and free primary education and secondary education on an equal basis with others in the community in which they live.”\textsuperscript{190} In line with its international obligations, Kyrgyzstan has an obligation to guarantee the right to free and compulsory primary education and secondary education, for all children.\textsuperscript{191} The CRPD Committee calls inclusive education “a fundamental right of all learners,” and fundamental to safeguarding persons with disabilities against exploitation and ensuring that they can access other key rights.\textsuperscript{192}

According to the committee, inclusive education should focus on the full and effective participation, accessibility, attendance, and achievement of all students, especially those who are at risk of being excluded or marginalized.\textsuperscript{193}

Inclusive education is distinct from segregation, whereby children are educated in environments specifically designed for their specific impairment, and integration, whereby children are placed in mainstream school environments with the understanding that they will adjust to the general requirements.\textsuperscript{194}

\textsuperscript{189} https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-11&chapter=4&clang=_en
\textsuperscript{190} CRPD art. 24.
\textsuperscript{191} CRPD, art. 24(2a); CRC, art. 28(i) (a) and (b).
\textsuperscript{192} CRPD General Comment 4, para. 10a and 10c.
\textsuperscript{193} CRPD and CRPD General Comment 4, para.
\textsuperscript{194} CRPD General Comment 4, para 11.
Some efforts to deinstitutionalize children with disabilities and enter them into mainstream schools without individualized educational responses or accommodations documented in this report, more closely resemble integration than inclusion.

Exclusion from education means the wholesale denial of access to education, whether directly, as in Kyrgyzstan’s case, the determination that some children, particularly those in institutions, are “uneducable,” and indirectly, such as imposing certain testing requirements for accessing school. According to the CRPD committee, any regulatory provision that would classify certain students as “non-educable” constitutes direct exclusion, and should be prohibited.

**Reasonable Accommodation**

As part of its stipulations on the right to inclusive education, the CRPD guarantees the right to reasonable accommodation of the individual’s requirements, defined as “necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case” to enjoy the full enjoyment of rights equal to others. Reasonable accommodation is distinct but complementary to general accessibility, which benefits groups of the population, in that it focuses on the specific needs of an individual.

The government should provide reasonable accommodations to support individual learning, including assistive devices such as hearing aids or specific software, braille textbooks, audio, video, and easy-to-read learning materials, instruction in sign language for children with hearing disabilities, structural modifications to schools, such as ramps for children in wheelchairs, and additional staff to assist children with self-care, behavior, or other support needed in the classroom. Individualized learning programs should be created to determine which reasonable accommodations are most effective for each student, and their implementation should be effectively monitored.

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195 Ibid., para 18.
196 CRPD General Comment No. 4 on the right to inclusive education, para. 18.
197 CRPD art. 24.
198 Ibid., art. 2.
199 CRPD General Comment 4, para. 29.
200 CRPD, art. 2, para. 4.
201 CRPD General Comment 4, para. 33.
The duty to provide reasonable accommodation “is enforceable from the moment a request for such accommodation is made.” The CRPD Committee calls on states to “recognize individual support and reasonable accommodation are priority matters and should be free of charge at all compulsory levels of education.”

Finally, teachers should be given training about inclusive teaching environments and be supported to learn how to give individualized instruction and how to teach in a way that is responsive to the learning styles and abilities of each person.

**Nondiscrimination**

International law prohibits discrimination on the basis of disability, defined in the CRPD as “any distinction, exclusion or restriction... which has the purpose or effect of impairing or nullifying the recognition, enjoyment or exercise, on an equal basis with others, of all human rights and fundamental freedoms.” Children and adults with disabilities should not be “excluded from the general education system on the basis of a disability.” In the international human rights framework, disability is recognized as an interaction of individuals with an environment that is either enabling or disabling. The emphasis should be on removing barriers and discrimination in that environment.

One goal of inclusive education is to enable communities to combat discrimination. The right to nondiscrimination “includes the right not to be segregated and to be provided with reasonable accommodation.” The obligation of nondiscrimination applies to both public and private actors.

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202 Ibid., Para. 28.
203 Ibid., Para. 17.
204 Ibid., Para. 71.
205 CRPD, Art. 2, para. 3.
206 CRPD, Art. 24, Para. 2a.
208 CRPD General Comment 4, para. 9.
209 Ibid., para. 13.
According to the CRPD, states also have an obligation to “undertake to provide early and comprehensive information, services, and support to children with disabilities and their families.”

### National Legal Standards

The rights of children with disabilities in Kyrgyzstan are enshrined in the constitution and in the following laws: The Law on Education, the Law on the Rights and Guarantees of People with Disabilities, and the Code on Children.

The Kyrgyz constitution guarantees the right to be free from discrimination on the basis of a disability, and specifically states that “there should be no limitation on the right… to receive free primary and secondary education in state educational institutions.”

The Law on the Rights and Guarantees of People with Disabilities says the “state guarantees people with disabilities the access to information, education, and professional training.” It extends the understanding of education to preschool, extracurricular, cultural and physical activities, and continuing education for adults. The Law on Education iterates this right in greater detail, again asserting the “equal rights of all citizens to a quality education.” The Law on the Status of the Teacher states that teachers must prevent “direct, hidden, or indirect discrimination,” including against children with disabilities.

However, the sections of the Law on Education that discuss disability emphasize *special*, separate settings for children with disabilities, both in special schools and at home, and therefore contravene the CRPD. The law specifically stipulates, “for children with impaired

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210 CRPD, Art. 23, para. 3.
214 Constitution, Article 16 Section 2.
215 Ibid., Article 20, Section 5-9.
physical or mental development, special groups, classes, or organizations are organized, guaranteeing them medical care, education and training, social adaptation and integration into society.” 218 A child can be sent to an organization for children with disabilities with a recommendation from the PMPC. Finally, the law states that “if there are medical indicators, the education of children with impaired physical or mental impairment can, with the agreement of the parent, be conducted individually, including home education.” 219 The law states that a list of medical conditions relevant for this decision will be determined by the Ministries of Education and Health.

The Code on the Child guarantees free medical care to children, as well as free medical rehabilitation for children with disabilities or chronic illness. 220

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219 Ibid., art. 33, para. 5.
V. Recommendations

To the Kyrgyz Government, including the Ministry of Labor and Social Development and the Ministry of Education:

Protect children and young people with disabilities in institutions from harm and abuse, and guarantee their rights to safety, inclusive education, play and leisure, through the following measures:

- Establish meaningful monitoring of all state institutions where children with disabilities live;
- Ensure that independent monitors, including civil society organizations, enjoy effective access to institutions and are able to make unscheduled as well as scheduled visits without unnecessary restrictions, which include confidential and private interviews with children and staff and observation and inspection of all parts of the institution;
- Create accessible and effective mechanisms for children with disabilities in state institutions to report abuse without risk of repercussions. This includes informing children in an accessible manner about their rights and ways in which to file complaints confidentially and receive psychological and legal assistance. Ensure children’s complaints are reviewed and addressed promptly and impartially;
- For as long as children with disabilities live in state institutions pending deinstitutionalization, ensure that they have access to inclusive education in mainstream schools in the community, adequate health care, rehabilitation, and play;
- End the use of inappropriate medication or placement in a psychiatric hospital as a means of punishing a child or controlling behavior; specifically, end the use of psychotropic medications counter-indicated for children. Instead, train staff in alternative methods and skills to de-escalate behavior;
- Ensure any forced medical intervention is strictly limited to emergency situations where the child’s life or health is exposed to imminent danger and lasts only until the immediate danger has subsided;
- Ensure the best interest of the child is paramount when deciding on necessary and appropriate medical treatment and that the views of children are meaningfully
heard and taken into account. Obtain consent from children when possible, and always obtain full consent from parents or other guardians acting in the interest of the child, including explanation of the treatment plan, alternative options, and expected outcomes;

- Ensure training for institution staff to support children in their custody to engage in advocacy on matters that concern them, including with regards to health care, psychiatric medications, and monitoring;

- Ensure all children in institutions participate in inclusive education in mainstream community schools, in line with the Committee of the Rights of Persons with Disabilities General Comment no. 4 (2016);

- Ensure the right to legal capacity, including an end to formal or informal policies or practices that deprive children with disabilities in institutions of their legal capacity upon reaching adulthood and guaranteeing young people aging out of institutions participate in court decisions concerning them, such as their legal capacity, and can receive legal assistance in such court processes;

- Abolish full guardianship and establish a deadline for review of previous court decisions depriving individuals with disabilities of their legal capacity. Create a system in which persons with disabilities are supported in making decisions rather than deprived of the ability to exercise rights.

**Improve the deinstitutionalization process through the following measures:**

- Eliminate discrimination in the deinstitutionalization process, including by guaranteeing that national deinstitutionalization policy includes children with disabilities equally with other children and includes the views of children with disabilities;

- Ensuring support for children with disabilities to live with their families, or in other family settings in the community including by beginning to redirect financial and other resources away from institutions and to children with disabilities, their families, and the establishment of community-based services;

- Until targeted, inclusive, community services are developed, in the short-term, identify and create opportunities to make the resources concentrated in institutions, such as rehabilitation services, medical services, therapies, medical and other specialists, and other services, available to children living in nearby
communities and their families, so that they may also benefit from such services while raising their children at home;

- Ensure that children with disabilities leaving institutions are supported during and after that transition, including by providing children and their families with financial and material support, information about and access to services, and access to mainstream schools including individual reasonable accommodations;

- Undertake transparent data collection on those children who have moved out of institutions and into families, including: where they are living, whether they are attending school, what discrimination or other barriers they encountered when enrolling or attending school, and whether they receive reasonable accommodations in response to their individual needs. The simple fact of a child being enrolled in a school should not be a marker of success unless their educational needs can be fully met, in line with Kyrgyzstan’s international obligations.

End discrimination and focus on guaranteeing quality and inclusion in education:

- Guarantee access to quality inclusive education for children with disabilities on an equal basis with others, including through the provision of reasonable accommodations, in line with the government’s international obligations. These can include braille textbooks and other materials, digital, visual, audio, easy-to-read learning materials, and assistive technology, instruction in sign language for children with hearing disabilities, and aides to assist students with additional support needs, self-care, learning support, and other considerations;

- In light of Kyrgyzstan’s “Concept on the Development of Inclusive Education,” amend legislation to define inclusive education in a way that is consistent with the CRPD and the Committee on the Rights of Persons with Disabilities’ General Comment No. 4 on inclusive education, in particular by:
  - Including a provision that mainstream schools are obliged to provide reasonable accommodations and quality education on an equal basis with others to children with disabilities, including access to individualized support measures;
  - Making clear that inclusive education is a right for every individual, regardless of disability, that cannot be denied based on a medical or other assessment by state bodies;
Promoting instruction and a teaching culture that moves away from a one-size-fits-all approach to learning towards one that can adapt to different learning abilities and styles, meets the diverse needs of all learners, recognizes that each student learns in a unique manner, and identifies and builds on the strengths and talents of each individual.

- Ensure all schools are physically accessible, including by ensuring they have ramps, that wheelchair users can navigate entrances to buildings, classrooms and toilets, and that new and old schools are designed and retrofitted, respectively, to comply with Universal Design standards, namely, the design and composition of an environment so that it may be accessed, understood, and used to the greatest extent possible with adaptation;
- Abolish the PMPC and redirect funds to schools or school districts to create dedicated professional teams to identify the reasonable accommodations necessary to meet individual requirements. These teams could invite students and parents or guardians to participate and share information about accommodations necessary to meet the students' needs; decisions about individualized education programs should be reviewed on a regular basis and the accommodation adjusted as necessary;
- Prohibit the MSCE or any other body from labeling children as “uneducable” or otherwise categorizing them according to supposed capacity to learn, prohibit the use of an MSCE evaluation or other medical documentation to formally or informally deny a child access to inclusive education;
- Improve access to information for children with disabilities and their parents about the right to inclusive education and the role of the PMPC and the MSCE. End any formal or informal practice permitting schools and other officials to rely on an assessment by the PMPC or MSCE to deny children access to education in mainstream schools;
- Ensure that home education is used only for short periods, and then only when absolutely necessary for health reasons work with local authorities and others to ensure that children are not restricted to home education due to a lack of transportation to and from local schools, or other barriers;
- Ensure that children with disabilities and their parents have real choices and access to adequate comprehensive information regarding their educational path. Children and parents should not feel compelled to opt for special schools or home
education due to failures of mainstream schools to provide reasonable accommodations for children;

- Throughout the development and implementation of policies and programs on inclusive education, consult regularly and meaningfully with children, their parents and other persons with disabilities, and disabled persons’ organizations;
- Enhance training on inclusive education for future school, vocational school, and higher education educators based on the human rights model of disability, including on means and formats of communication, educational techniques and materials to support persons with disabilities; incorporate practical training, including with and by people with disabilities.

Data Collection:

- In line with international practices and standards, including on protection of data privacy and confidentiality, collect and preserve data on the total number of children with disabilities in the country, including the number of children of compulsory school age in education and out of school, disaggregated by disability-type, location, and other demographic markers; use the data to formulate educational policies, plans, and programs;
- Collect and make publicly available statistics on the number of children and adults with disabilities in various parts of the education system in Kyrgyzstan; include annual attendance numbers and rates in all categories of schools, vocational colleges, and higher educational institutions, as well as children studying at home, disaggregated by age, gender, and type of disability;
- Conduct an investigation into home education and publish data about those children receiving home education, including number of contact hours, teachers deployed, the number of years children spend in home education, and what evaluations of children’s performance are conducted during home education.

To the EU in its role supporting the deinstitutionalization process:

- Ensure effective and transparent monitoring of the deinstitutionalization process;
- Through the EU’s implementing partners, provide sustained support to families of children who are removed from an institution or residential special school. The EU should not support, including through funding, any substantial construction work for existing institutions, as this helps perpetuate institutionalization. Financial and
other forms of support should be earmarked toward community-based and individual support services for children with disabilities and their families;

- Urge and support the government to undertake transparent data collection on those children who have moved out of institutions and into families, including: where they are living, whether they are attending school, what discrimination or other barriers they encountered when enrolling or attending school, and whether they receive reasonable accommodations in response to their individual needs. The simple fact of a child being enrolled in a school should not be a marker of success unless their educational needs can be fully met, in line with Kyrgyzstan’s international obligations.

To Kyrgyzstan’s international partners:

- Support a full transition to inclusive education and redirect any funding or support that may perpetuate or reinforce the segregation of children with disabilities to initiatives that promote inclusive education and the right to live in the community;

- Urge the Kyrgyz government in private and in public meetings to ensure the rights of people with disabilities, including the right to live independently in the community, with support as necessary, and the right to inclusive, quality education for children with disabilities, and continue supporting the government in its efforts to do so, including through financial and technical means;

- Share models of good practices with Kyrgyzstan on guaranteeing quality, inclusive education for children and adults with disabilities on an equal basis with others, at all levels of education and on ensuring the right to live in the community;

- Consistently consult with and ensure disabled persons’ organizations, as well as NGOs working on disability rights, inclusive education, and children’s rights, are included in and benefit from donor support;

- Ensure that all development projects implemented in Kyrgyzstan comply with the international accessibility and universal design standards and are inclusive of and accessible to persons with disabilities;

- Support the government to improve systematic data collection on children with disabilities by age, gender, disability, and educational access.
Acknowledgments

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Appendix I: Letter from the Ministry of Labor and Social Development to Human Rights Watch

Исполнительному директору Отделения «Human Rights Watch» по Европе и Центральной Азии
Х. Уильямсон

Уважаемый господин Хью Уильямсон,

Министерство труда и социального развития Кыргызской Республики (далее-Министерство) направляет промежуточную информацию по вашему запросу относительно соблюдения прав детей с инвалидностью в учреждениях интернатного типа.

В целях защиты прав и улучшения качества жизни лиц с ограниченными возможностями здоровья в Кыргызской Республике принят Закон Кыргызской Республики «О ратификации Конвенции ООН о правах инвалидов, принятой Генеральной Ассамблеей Организации Объединенных Наций 13 декабря 2006 года и подписанной 21 сентября 2011 года» (от 14 марта 2019 года № 34).

В соответствии со статьей 1 вышеуказанной Конвенции государственные участники обязуются обеспечивать и поощрять полную реализацию всех прав человека и основных свобод всеми инвалидами без какой бы то ни было дискриминации по признаку инвалидности. С этой целью государственные участники обязуются принимать все надлежащие законодательные, административные и иные меры для осуществления прав, признаваемых в настоящей Конвенции.

С целью эффективного удовлетворения потребностей детей-инвалидов на недискриминационной основе, принято постановление Правительства Кыргызской Республики от 23 ноября 2018 года № 556, согласно которому с 1 января 2019 года в Кыргызстане введен новый вид социальной услуги - «персональный ассистент» в целях оказания услуг детям с ограниченными возможностями здоровья и нуждающимся в постоянном постороннем уходе и надзоре, а также для реализации прав таких детей на семейное окружение.

В Кыргызской Республике по состоянию на 1 января 2020 года проживает 193,8 тыс. ЛОВЗ, в том числе – 32,0 тыс. детей с ограниченными возможностями здоровья. На 1 января 2020 года по всей республике количество оказывающих услуги персонального ассистента составляет – 6476 человек, а получатели услуг персонального ассистента – 6557 детей.

В целях обеспечения безопасности сотрудников в сложной ситуации в стране с эпидемией коронавируса, многие сотрудники государственных органов, в их числе сотрудники Министерства, отправлены на удаленную работу или в трудовые отпуска. В этой связи, Министерством будет направлена расширенная информация по вашему запросу после снятия режима чрезвычайной ситуации.

Заместитель министра

А.Солтонбекова

Изд.: Т.Т. Койчуманов, тел.: 62 45 21
Appendix II: Human Rights Watch Letter to the Ministry of Labor and Social Development

May 21, 2020

Dear Mr. Kochkozov,

On behalf of Human Rights Watch, please accept my best regards.

As you know, Human Rights Watch is an independent international organization that works in over 90 countries to defend people's rights. Human Rights Watch does not receive funding from any government. Our organization has conducted research on the rights of people with disabilities in dozens of countries around the world.

We value the engagement we have with the Ministry of Labor and Social Development during this process. We would particularly like to thank you for meeting with us in February and for assisting us in obtaining permission to visit the Beloved City and Jalalabads' Psychoneuropsychiatric Institute. We are also aware of a number of positive policy steps taken by the Ministry of Labor and Social Development to support families with disabilities, including the introduction of a new “assistant” payment to families of children with high-support needs.

As a part of our ongoing work on the rights of persons with disabilities, Human Rights Watch has undertaken research on the conditions and treatment of children and young adults with disabilities in residential homes or schools, including psychoneuropsychological institutions. We have also conducted research into the ability of children with disabilities to access inclusive education, and specifically the role that the Medical-Social Expertise (MSE) plays in that sphere. Over the last year, Human Rights Watch conducted interviews with over 100 children with disabilities, their parents, experts, and disability rights activists in several cities in Kyrgyzstan about these two issues. We also reviewed legislation and government policies pertaining to these topics.

We write to you now in the spirit of constructive engagement to share with the Ministry of Labor and Social Development our preliminary findings. We also write to ask the questions listed below regarding conditions in institutions under the authority of the ministry, as well as questions pertaining to inclusive education.
The results of our research will be published in a report. We would appreciate it if we could receive your response by June 30, 2020 so as to ensure we fully reflect your answers in the report. We hope our findings and recommendations will be useful for Kyrgyzstan as it seeks to guarantee the rights of children with disabilities.

**Preliminary Findings Relevant to the Ministry of Labor and Social Development**

**On Institutions**

Kyrgyzstan has ratified the Convention on the Rights of the Child (CRC) and just last year ratified the Convention on the Rights of Persons with Disabilities (CRPD). These treaties recognize that children have a right to grow up in a family environment and be included in the community regardless of any disability. They also guarantee the right to be free from violence and neglect.

However, in the course of our research, we found that children and young adults who grow up in psychoneurological institutes (PNIs) face isolation and neglect. Institution staff also told us they have no accessible or age-appropriate complaint mechanisms in place for a child to report physical or verbal abuse.

We found that caretakers in PNIs, who often felt that they were understaffed, relied on the administration of antipsychotics, sedatives, and other medications, not for a legitimate therapeutic purpose but rather to respond to behaviors deemed disruptive. It did not appear that caretakers attempted to adapt less intrusive interventions in response to a child’s behavior, such as teaching them positive coping mechanisms, improving communication skills, or conducting group therapy.

It also did not appear that medical staff made an effort to reach out to the parents or legal guardians of the children to explain the rationale for using these medications or explain side effects, nor did they obtain consent for their use. In cases where children did not have legal guardians or parents, institution staff made no attempt to obtain consent from children or inform them in any way in this process. While international law recognizes that children can be treated with consent of a parent or guardian, the CRC stresses the importance of children’s participation in this process.

Finally, we found that upon reaching 18, children in psychoneurological institutes are often denied legal capacity, and a decision is made to either to send them to an institution for adults or to grant guardianship to their parents or other relatives.
Human Rights Watch is concerned that the PNIs have been excluded from the government’s current plan to close or transform institutions for children across the country.

**On the MSCE**

A large part of our research focused on barriers faced by children living in the community in accessing quality inclusive education. We understand that primarily it is the role of the Psycho-Medico Pedagogical Commission (PMPC), overseen by the Ministry of Education, to assess children with disabilities and make recommendations for their educational path. However, due to the limited geographic reach of the PMPC, most parents we spoke to underwent only the Medico-Social Expert Commission (MSCE), and not the PMPC. Many parents said that a conclusion from the MSCE, which was demanded by schools upon a child’s attempt to enroll, could be used as grounds for barring a child from receiving education in a mainstream school, and for referring them for homeschooling or to a special school instead.

Our understanding is that MSCE is conducted by medical professionals, most of whom likely lack pedagogical or disability rights expertise. Affirmation of the right to inclusive education is part of an international shift from a “medical model” of viewing disability to a “social model,” which recognizes disability as an interaction between individuals and their environment, with an emphasis on identifying and removing discriminatory barriers and attitudes in the environment.

We kindly request the Ministry of Labor and Social Development to provide us with the following information:

**On Institutions for Children:**

1. Could your ministry kindly provide data on how many children with disabilities currently reside in the two psychoneurological institutes (PNIs) for children under your authority, and disaggregate the number by age, gender, and type of disability?

2. How many children were residing in institutions for children, other than PNIs, overseen by the Ministry of Social Development in each of the last five years? Could you disaggregate this data by age, gender, and type of disability?

3. How many of the total number of children with disabilities currently residing in PNIs have at least one living parent?

4. What is the standard ratio of children with disabilities to caregivers in these PNIs?
Human Rights Watch is concerned that the PNIs have been excluded from the
government's current plan to close or transform institutions for children across the
country.

On the MSCE
A large part of our research focused on barriers faced by children living in the community
in accessing quality inclusive education. We understand that primarily it is the role of the
Psycho-Medico Pedagogical Commission (PMPC), overseen by the Ministry of Education, to
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parents said that a conclusion from the MSCE, which was demanded by schools upon a
child's attempt to enroll, could be used as grounds for barring a child from receiving
education in a mainstream school, and for referring them for homeschooling or to a special
school instead.

Our understanding is that MSCE is conducted by medical professionals, most of whom
likely lack pedagogical or disability rights expertise. Affirmation of the right to inclusive
education is part of an international shift from a "medical model" of viewing disability to a
"social model," which recognizes disability as an interaction between individuals and their
environment, with an emphasis on identifying and removing discriminatory barriers and
attitudes in the environment.

We kindly request the Ministry of Labor and Social Development to provide us with the
following information:

On Institutions for Children:
1. Could your ministry kindly provide data on how many children with disabilities
currently reside in the two psycho-neurological institutes (PNIs) for children under
your authority, and disaggregate the number by age, gender, and type of disability?

2. How many children were residing in institutions for children, other than PNIs,
ever seen by the Ministry of Social Development in each of the last five years? Could
you disaggregate this data by age, gender, and type of disability?

3. How many of the total number of children with disabilities currently residing in PNIs
have at least one living parent?

4. What is the standard ratio of children with disabilities to caregivers in these PNIs?
5. What government policies or regulations, if any, regulate workers at PNs regarding the following practices:
   a. The use of physical restraints, such as to bind children’s hands to their bodies;
   b. The use of sedatives or antipsychotic medication;
   c. The use of corporal punishment or other physical force by staff or other children as punishment for behavior deemed disruptive;
   d. Overall guidance on disciplinary measures.

6. What measures have been adopted to ensure that health care services in PNs are based on the free and informed consent of the person concerned, including children?

7. What measures have been taken to oversee the prescription of medications, including psychotropic medication, to children in institutions? Does the Ministry collect any data on how frequently and in what quantity these medications are used in PNs?

8. What mechanisms are put in place to inform the child and the child’s guardian about the potential risks and benefits of prescribed medication?

9. What training in non-coercive, constructive interventions do staff employed at PNs for children receive?

10. Which government body is responsible for monitoring conditions in PNs for children to ensure that they are consistent with national and international standards? What are the results of that monitoring? What, if any, measures are in place to hold institution workers accountable in cases of physical or psychological violence, or neglect of a child?

11. Under what circumstances are children from PNs placed in psychiatric hospitals, and for how long?

12. Under what circumstances are children from PNs transferred to adult institutions after reaching adulthood? How many have been transferred to institutions for adults in the last five years upon reaching adulthood? How many children were reunited with their families upon reaching adulthood?
13. How many children died in the last five years while in the custody of PHIs for children?

14. What are the reasons for initiating procedures to deprive children living in PHIs of their legal capacity upon reaching adulthood? Are there any protocols regulating this process, or guidance for courts or institution staff on how they can facilitate assisted-decision making that fully supports an individual’s exercise of their rights during this process?

15. Do all children in PHIs undergo a court process to determine their legal capacity? If so, can you share any data on these court rulings from recent years?

16. Is an individual who is subject to deprivation of legal capacity able to participate in person in all court proceedings related to that deprivation of legal capacity?

17. How many adults with disabilities in Kyrgyzstan are deprived of legal capacity?

18. Does the government plan to phase out the use of PHIs for children, including by prioritizing family-based care, preventing new placements of children in institutions, and ensuring community-based supports for children with disabilities and their families? If so, when?

19. Does the ministry have any plans to include the PHIs for children in the government’s deinstitutionalization plan? If so, when do you anticipate this will take place?

20. What, if any, policies have been put in place in PHIs in response to the Covid-19 pandemic? Under what conditions will those policies be lifted?

Questions pertaining to the MSCE:

1. According to the “Government Decree on the Medico-Social Expertise in the Kyrgyz Republic,” the MSCE can rule that a child is capable of study in a mainstream school, capable of study in a special school or should be homeschooled, or is not capable of being educated at all. We would like to understand:
   a. What protocols or guidance regulate MSCE employees’ decision to issue recommendations on a child’s educational path?
   b. Can you provide any information on how many children were ruled 1) fit for study in a mainstream school; 2) fit for study in a special school; 3) fit for
homeschooling; and 4) not capable of being educated at all in 2019, respectively?

2. What policies exist regulating the MSCE or providing guidance to its members, beyond the “Government Decree on the Medico-Social Expertise in the Kyrgyz Republic” of 2002?

3. How many MSCE offices are there in the country? How many of them operate full-time, and how many of them operate part-time?

4. How many children did MSCE assess in 2019?

5. In the case of a child with a disability, how many people make up the MSCE and what professional qualifications do they have? Are any non-medical personnel ever included in the assessment of a child for the MSCE, and, if so, in what instances?

6. Are members of the MSCE provided with any training or guidance on the rights of children with disabilities, and, if so, what?

7. Are there any policies regulating how school administrators and teachers, including those who work in special schools, should use information from the MSCE in making a decision to enroll the child or enlist them in homeschooling? Are decisions by the MSCE “mandatory” or “recommendatory” in nature, and where is this explicitly stated?

8. What policies guide cooperation between the MSCE and the PMPC, particularly in light of education for children with disabilities? Are there policies that require or encourage MSEE employees to refer parents to a PMPC?

9. The Ministry has said it plans to reform the MSCE by bringing it in line with the International Classification of Functioning, Disability and Health. What is the timeline of these reforms and what has been accomplished to date?

10. Does the Ministry have any additional plans to further reform the MSEE, and if so what?

https://ishg.gov.kg/ru/sozornoe-spravlenie/
We thank you for your attention to these questions and look forward to receiving your response.

Thank you once again for your engagement on this issue and the constructive dialogue between our offices.

We ask you to kindly send your response to my colleagues Laura Mills (by email at mills@hrw.org or by phone at +1-917-366-3288) and Alchanbek Kurmanbekov (+996 555991023). Please do not hesitate to contact Mrs. Kurmanbekova or Ms. Mills with any questions in the meantime.

Kind regards,

[Signature]

Hugh Williamson  
Director, Europe and Central Asia Division  
Human Rights Watch
May 21, 2020

Dear Mr. Isakov,

On behalf of Human Rights Watch, please accept my best regards.

As you know, Human Rights Watch is an independent international organization that works in over 90 countries to defend people’s rights. Human Rights Watch does not receive funding from any government. Our organization has conducted research on the rights of people with disabilities in dozens of countries around the world.

We commend Kyrgyzstan for its ratification of the Convention on the Rights of Persons with Disabilities (CRPD) last year, which underscored its commitment to guaranteeing the right to quality, inclusive education for people with disabilities. We are aware of positive policy initiatives regarding protection of the rights of people with disabilities, including the “Concept on Inclusive Education” announced in July 2019, and several inclusive education pilot programs backed in part by international organizations.

Over the last year, Human Rights Watch has conducted interviews with over 100 children with disabilities, their parents, experts, and disability rights activists in several cities in Kyrgyzstan about their experiences accessing inclusive education, including experiences at the Psycho-Medical Pedagogical Consultations (PMPC). We also visited four residential special schools in Osh, Uch-Kordor, and Chuy regions. We reviewed legislation and government policies regarding inclusive education.

We write to you now in the spirit of constructive engagement to share with the Ministry of Education our preliminary findings. We also write to ask the questions listed below regarding progress toward guaranteeing inclusive education, and other steps your ministry has taken to meet its international obligations in line with the CRPD.

The results of our research will be published in a report, and we ask that you please respond to our questions by June 15, 2020 so as to ensure that we
have adequate time to reflect your views. We hope our findings and recommendations will be useful for Kyrgyzstan as it seeks to ensure access to quality, inclusive education for all children with disabilities.

Preliminary Findings Relevant to the Ministry of Education
On Special Residential Schools

In the course of our research we found that children and young adults in special residential schools face isolation and neglect. We also note that there are no accessible or age-appropriate complaint mechanisms in place for a child to report physical or verbal abuse or negligent practices. In fact, most residential schools banned the use of phones except in front of a caretaker, clearly limiting a child's ability to report abuse to their parent or relative in a confidential and private manner.

We found that staff in residential special schools used forced psychiatric hospitalization to control behaviors they deemed problematic. Our review of medical documentation showed that children were treated with antipsychotics and sedatives while there. It is not clear that parents gave informed consent to the use of these medications, or were given any explanation as to their use or potential side effects before consenting to the treatment. If children did not have parental guardians, the staff signed off on treatment themselves and made no attempts to obtain consent from children or involve them in their treatment plan in any way. While international law recognizes that children can be treated with consent of a parent or guardian, the Convention on the Rights of the Child (CRC) stresses the importance of children's participation in this process.

Parents of children with disabilities complained that the quality of education provided in residential special schools was unsatisfactory. Teachers said that while these schools provide eight or nine years of education, it was equivalent to a four-year education in a mainstream school. They also said they were banned from giving failing grades. Parents said there was a lack of individual attention given to children with higher support needs, and a noted lack of speech therapy in particular, which many children in special schools for children with intellectual disabilities desperately need.

On Inclusive Education

Human Rights Watch found that a number of barriers contribute to the exclusion of children with disabilities from mainstream education.
These include discriminatory barriers to enrollment. Our research shows that the Psycho-Medico Pedagogical Committee (PMPC) decisions, which are purportedly non-binding and should be limited to providing recommendations about a child's educational path, often lead to the segregation of a child with a disability, either in a special school or in homeschooling. While we spoke to some parents who were able to enroll their child in a mainstream school contrary to a decision by the PMPC, this was often only possible after insistence of and support from disability rights groups and NGOs. Our research suggests that many parents lack relevant information about how to enroll their child in a mainstream school contrary to a PMPC decision, and feel compelled to follow the commission's recommendation. Some parents also raised concerns about the quality and accuracy of the PMPC assessments that led to these recommendations.

The PMPC has limited reach: only a few of the children with disabilities interviewed for this report had undergone the PMPC, most of them in or near Bishkek. The remaining parents had, in most cases, never heard of the PMPC, and instead used documentation from the Medico-Social Expertise Commission (MSCE) when attempting to enroll their children in school. As you know, this committee is primarily made up of medical experts who are unlikely to have any specific pedagogical training. Children were often excluded from mainstream schools and either referred to a special school or homeschooled on the basis of a conclusion by the MSCE.

Human Rights Watch’s research found that when mainstream schools did admit children with disabilities, they did not provide reasonable accommodations—defined as a “necessary and appropriate modification or adjustment” to support a child’s learning—for them. Children with disabilities studying in mainstream schools said they have limited physical accessibility, including inside the buildings and toilets. Schools lacked sufficient staff, such as support aides, to assist children in the classroom. Our research also found that in some schools, the academic programs lack flexibility or do not have teaching materials to accommodate children with particular learning needs. The teaching of braille or sign language is virtually unheard of in mainstream schools.

We would be grateful if the Ministry of Education could provide information and data to the following questions:

Data
1. How many children with disabilities live in Kyrgyzstan? How many are boys, and how many are girls?

2. Can you please provide information regarding how children (age 6-16) and teenagers (age 16-18) with disabilities are being educated in each of the following ways, disaggregated by disability:
   a. Educated in mainstream schools on a full-time basis;
   b. Educated in mainstream pre-school or kindergarten on a full-time basis;
   c. Homeschooled with partial attendance of a mainstream school;
   d. Homeschooled with no attendance of a mainstream school;
   e. Enrolled in a special school;
   f. Enrolled in a special preschool or kindergarten;
   g. Not receiving any kind of education;

**Special Schools**

3. Can you please provide data for:
   a. the total number of special schools in Kyrgyzstan;
   b. the total number of children who study at residential special schools, and the number that live there.

4. Does the government of Kyrgyzstan plan to open any new special schools in the next five years?
   a. If yes, how many? Which parts of the country?
   b. Will these be residential or non-residential schools?

5. What are the policies currently regulating the amount and standard of speech therapy provided in special schools?

6. What measures were taken at special residential schools in response to the Covid-19 pandemic? In particular, what happened to those children who do not have parental guardians?

**Deinstitutionalization of Special Residential Schools**

7. We understand that three special residential schools were included in Kyrgyzstan’s deinstitutionalization plan. Can you confirm which special residential schools are participating in the plan, and how many children from each school have been reunited.
with their families? How many children have been transferred to other institutions or special residential schools for children with disabilities?

8. Have you conducted any monitoring or data collection on the quality of education children receive once they leave a special residential school and return to live at home?
   a. How many of these children have been enrolled in mainstream schools, and how many are homeschooled?
   b. Do you collect any information about the type or level of support they need and are not being provided within a mainstream school?

9. When do you expect deinstitutionalization of residential schools currently part of the plan to be complete? Are there plans to transform or close more residential special schools, and if so, when?

PMPC

10. How many children are evaluated by all Kyrgyzstan’s PMPC offices each year? Can you please provide any disaggregated information for the number of children evaluated in each region?

11. How many PMPC conclusions result in:
   a. A child being placed in a mainstream school?
   b. A child being placed in a special school?
   c. A child being homeschooled?
   d. A child not receiving any form of education?

12. How many PMPC offices operate year-round? Of those PMPC offices that do not work year-round, how many days per year do they work?

13. What policies or protocols exist regulating the PMPC? Can you please share a copy?

14. What guidelines are in place to ensure that children with disabilities are assessed by PMPC in conditions conducive to protecting the best interests of the child?
15. Is a PMPC decision recommendatory or required for children with disabilities to attend mainstream schools? Could you please provide further details on the guidance provided to school officials on how they should interpret PMPC decisions?

16. We found that many children with disabilities were seen not by the PMPC but by the MSCE, overseen by the Ministry of Labor and Social Development. How does your ministry cooperate with the MLSO regarding the educational path of a child with a disability? Are employees of the MSCE instructed to recommend a child undergo evaluation by the PMPC, or vice versa?

Mainstream Schools
17. How does the Ministry of Education ensure that mainstream schools are accessible to all children with disabilities? What recourse do parents and children have when school administrators deny admission to children with disabilities?

18. We are aware that UNICEF is currently piloting a project for several inclusive schools across the country. Can you please tell us:
   a) What is the Ministry of Education's role in this project? Does the Ministry or other state actors have any role in financially supporting this project at this time?
   b) How many "inclusive schools" exist outside of this UNICEF project in Kyrgyzstan? What are the criteria used to determine that a school meets the standards of inclusion?

19. Some experts told us of the existence of a "3 coefficient," or a 30% increase in pay for teachers working with children with disabilities in mainstream schools. What policies exist regulating the distribution of this coefficient? How many teachers, or schools, have been granted this coefficient, and how do they go about accessing it?

20. How does the government monitor enrollment of children with disabilities in inclusive schools, including to ensure that these children are in fact enrolled when schools report that they are?

Homeschooling
21. Which policies or protocols regulate the standards of homeschool education? Are children who are homeschooled expected to meet the same requirements as other students? What monitoring systems have been put in place to ensure quality education in homeschooling?

22. What policies or protocols exist regulating the length of time for which a child can be homeschooled? What steps is the government taking to reach children who are homeschooled and include them in mainstream schools?

23. What support or training on teaching children with disabilities is given to teachers who are responsible for homeschooling of these children?

24. What is the minimum and maximum of in-person contact hours between a teacher and a child when the child is being homeschooled?

**Higher and Vocational Training**

25. How many people and with what types of disabilities are enrolled in higher education in Kyrgyzstan?

26. Does the Ministry of Education offer any adult schooling options for people with disabilities, including for those people who did not have access to education as children?

**General Questions**

27. What steps have been taken so far towards implementation of the government’s Concept on Inclusive Education from July 2019? Has any relevant legislation been proposed or passed?

28. Does a definition of reasonable accommodation exist in any Kyrgyz law or regulations? Are there plans to incorporate a definition of reasonable accommodation based on the CRPD, as well as define the denial of reasonable accommodation as prohibited grounds for discrimination in all spheres of life, in line with CRPD Committee recommendations?

29. How does the Ministry of Education plan to provide reasonable accommodations, including accessible educational materials, modified curricula, aides to students who
require them, and other support for children with disabilities, to ensure that they can study in mainstream schools and receive a quality education on an equal basis with other children?

30. What steps is the Ministry of Education taking to ensure physical accessibility of school buildings, including classrooms, toilets and all relevant spaces used by children and staff, and transportation to and from school for children with disabilities?

31. What is the Ministry of Education doing to ensure that all teachers working in mainstream schools in Kyrgyzstan receive, including through ongoing professional development courses, training in inclusive education? What kind of training do teachers receive in inclusive education, and how often?

32. How does the Ministry of Education promote awareness about the right of children with disabilities to attend schools in the general education system?

33. How is the responsibility for ensuring access to inclusive, quality education organized between different levels of government? Between different ministries?

34. Is the decision to allocate resources towards ensuring inclusive, quality education for children in Kyrgyzstan made at a local, regional, or national level?

35. How does the Ministry of Education ensure that adequate and equitable resources are allocated such that all children in Kyrgyzstan have equal access to inclusive education?

36. How much of your budget (in Kyrgyz soms) has been allocated to the development of inclusive education initiatives or schools?

We thank you for your attention to these questions and look forward to receiving your response.

Thank you once again for your engagement on this issue and the constructive dialogue between our offices.

We ask you to kindly send your response to my colleagues Laura Mills (by email at miliisahow.org) or by phone at +1-917-366-7083) and Aishurken Kurmanbekova (+996
Please do not hesitate to contact Ms. Kurmanbekova or Ms. Mills with any questions in the meantime.

Kind regards,

Hugh Williamson
Director, Europe and Central Asia Division
Human Rights Watch
Appendix IV: Human Rights Watch Letter to the Ministry of Health

May 21, 2020

Dear Mr. Abdikarimov,

On behalf of Human Rights Watch, please accept my best regards.

As you know, Human Rights Watch is an independent international organization that works in over 90 countries to defend people’s rights. Human Rights Watch does not receive funding from any government. Our organization has conducted research on the rights of people with disabilities in dozens of countries around the world.

Since October 2019, we have conducted over 120 interviews on this subject in Kyrgyzstan, specifically with regards to the rights of children with disabilities in state institutions or residential schools. During this process, we learned that many children with disabilities in institutions and special residential schools are frequently prescribed antipsychotics and sedatives, particularly Aminazine, Azaeleptol, and Phenobarbital.

Interviews with staff in psychoneurological institutes (PNIs) for children suggested that these medications are used as a chemical restraint, i.e. as a means of preventing behavior deemed difficult by staff, rather than for specified therapeutic purposes. Human Rights Watch is concerned that important consent procedures appear to be lacking in these cases. In cases where a child has a parent or legal guardian, they are not regularly or comprehensively informed about the use of these medications, the expected treatment outcome, potential side effects, or alternative treatment. Human Rights Watch has not been able to verify whether children are informed or consulted about the use of these medications.

In special residential schools, we learned that most facilities do not have the medical staff required to administer these types of medications onsite. However, we learned that children whose behavior is deemed problematic by staff are often sent to outside psychiatric hospitals for disciplinary purposes, where they are treated with the same medications mentioned above. Yet again, it is unclear how comprehensively parents are informed about these processes, and children without parents are sent for treatment with a sign-off from only the institution director.
We write to you in the spirit of constructive engagement to better understand the protocols regulating the use of these medications in children. We would appreciate if you could respond to our questions by June 15, 2020 so as to allow us to comprehensively reflect your views and information in a report we hope to publish in the autumn.

1. What guidelines or protocols regulate the use of psychotropic medication in children? Could Human Rights Watch receive a copy of these guidelines or protocols?

2. What procedures are in place to ensure that children with disabilities receive psychotropic medication that is licensed and approved for children in Kyrgyzstan? Is there a list of approved and licensed medication for use in children? If yes, could Human Rights Watch receive a copy of the list?

3. What is the legal framework and what guidance exists on the use of psychotropic medication as a chemical restraint for children with disabilities?

4. What measures have been adopted to ensure that health care services, including the use of psychotropic medication in children, is based on the free and informed consent of the person concerned, including a child or an adult deprived of legal capacity?

5. What training do health workers receive regarding non-invasive ways to support children in case of challenging behavior?

6. What role does the Ministry of Health play in overseeing the prescription of medications, including psychotropic medications, in psychoneurological institutions for children? Does it conduct any regular monitoring or review of healthcare workers and facilities within these institutions?

7. Is there an oversight mechanism to protect children with disabilities from forced medication used to control their behavior?

8. Who is responsible for giving consent to psychiatric treatment when a child is in state custody, for example at a special residential school? Are there any protocols or mechanisms to regulate this procedure?
We thank you for your attention to these questions and look forward to receiving your response. Please send your response to my colleague, Laura Mills (by email at
millsldhrw.org or by phone at +1-917-836-9688) or Aichurek Kurmanbekova (by email at
kurmanak@hrw.org or by phone at +996 555991023). Please do not hesitate to contact
either of them with questions in the meantime.

Kind regards,

Hugh Williamson
Director, Europe and Central Asia Division
Human Rights Watch
Appendix V: Human Rights Watch Letter to the Ministry of Justice

May 21, 2020

Dear Mr. Abdikarimov,

On behalf of Human Rights Watch, please accept my best regards.

As you know, Human Rights Watch is an independent international organization that works in over 90 countries to defend people's rights. Human Rights Watch does not receive funding from any government. Our organization has conducted research on the rights of people with disabilities in dozens of countries around the world.

Since October 2019, we have conducted over 120 interviews on this subject in Kyrgyzstan, specifically with regard to the rights of children with disabilities in state institutions or residential schools. During this process, we learned that many children with disabilities in institutions and special residential schools are frequently prescribed antipsychotics and sedatives, particularly Aminzepin, Azaletopil, and Phenoabarbitals.

Interviews with staff in psychoneurological institutes (PNIs) for children suggested that these medications are used as a chemical restraint, i.e. as a means of preventing behavior deemed difficult by staff, rather than for specified therapeutic purposes. Human Rights Watch is concerned that important consent procedures appear to be lacking in these cases. In cases where a child has a parent or legal guardian, they are not regularly or comprehensively informed about the use of these medications, the expected treatment outcomes, potential side effects, or alternative treatments. Human Rights Watch has not been able to verify whether children are informed or consulted about the use of these medications.

In special residential schools, we learned that most facilities do not have the medical staff required to administer these types of medications onsite. However, we learned that children whose behavior is deemed problematic by staff are often sent to outside psychiatric hospitals for disciplinary purposes, where they are treated with the same medications mentioned above. Yet again, it is unclear how comprehensively parents are informed about these processes, and children without parents are sent for treatment with a sign-off from only the institution director.
We write to you in the spirit of constructive engagement to better understand the protocols regulating the use of these medications in children. We would appreciate if you could respond to our questions by June 15, 2020 so as to allow us to comprehensively reflect your views and information in a report we hope to publish in the autumn.

1. What guidelines or protocols regulate the use of psychotropic medication in children? Could Human Rights Watch receive a copy of these guidelines or protocols?

2. What procedures are in place to ensure that children with disabilities receive psychotropic medication that is licensed and approved for children in Kyrgyzstan? Is there a list of approved and licensed medication for use in children? If yes, could Human Rights Watch receive a copy of the list?

3. What is the legal framework and what guidance exists on the use of psychotropic medication as a chemical restraint for children with disabilities?

4. What measures have been adopted to ensure that health care services, including the use of psychotropic medication in children, is based on the free and informed consent of the person concerned, including a child or an adult deprived of legal capacity?

5. What training do health workers receive regarding non-invasive ways to support children in case of challenging behavior?

6. What role does the Ministry of Health play in overseeing the prescription of medications, including psychotropic medications, in psychoneurological institutions for children? Does it conduct any regular monitoring or review of healthcare workers and facilities within these institutions?

7. Is there an oversight mechanism to protect children with disabilities from forced medication used to control their behavior?

8. Who is responsible for giving consent to psychiatric treatment when a child is in state custody, for example at a special residential school? Are there any protocols or mechanisms to regulate this procedure?
We thank you for your attention to these questions and look forward to receiving your response. Please send your response to my colleague, Laura Mills (by email at millslohnw.org or by phone at +1-917-836-9688) or Aichune Kurmanbekova (by email at kurmanaa@hrw.org or by phone at +996 555991023). Please do not hesitate to contact either of them with questions in the meantime.

Kind regards,

Hugh Williamson
Director, Europe and Central Asia Division
Human Rights Watch
Appendix VI: Human Rights Watch Letter to the Ministry of Foreign Affairs

European and Central Asia Division

Appendix VI: Human Rights Watch Letter to the Ministry of Foreign Affairs

May 21, 2020

Reference N° 13/20-2105

Mr. Aldarbekov Chingiz Azamatovich
Minister of Foreign Affairs of the Kyrgyz Republic
Erkindik Boulevard 57, 720040 Bishkek, Kyrgyzstan

Tel: (+996-312) 6205451; (+996-312) 626559
Email: gerefaa@moda.gov.kg; pressalsaibat@gmail.com

Dear Minister Chingiz Azamatovich,

On behalf of Human Rights Watch, please accept my regards.

As you know, Human Rights Watch is an independent international organization that works in over 90 countries to defend people’s rights.

We recently conducted research on the rights of children with disabilities in Kyrgyzstan. Our research revealed human rights abuses in institutions and special residential schools for children with disabilities. We also found that children with disabilities who still live with their families face discriminatory barriers when attempting to access quality, inclusive education. Since October 2019, we have conducted over 120 interviews with children with disabilities, their parents, experts, and disability rights groups on this subject. We plan to publish our findings in a report later this year.

Human Rights Watch kindly requests the assistance of the Ministry of Foreign Affairs in distributing the attached letters with our preliminary findings and requests for information to the following Kyrgyz Republic ministries: the Ministry of Education, the Ministry of Labor and Social Development, the Ministry of Health, and the Ministry of Justice. We request that you forward any responses to these questions from the ministries to us. Responses from government officials will inform our findings and will be reflected in our report.

In order to ensure adequate time to reflect your views, we kindly request that you send us any responses by June 15, 2020.

Human Rights Watch


INSISTING ON INCLUSION 100
Please send any responses to my colleague in Bishkek, Ms. Almurek Kurmanbekova (at
laura@hrw.org or by mob. 0555991023), or Ms. Laura Mills in New York at
mills@hrw.org
+1-917-836-9883. Please do not hesitate to contact Ms. Kurmanbekova or Ms. Mills with any
questions in the meantime.

Thank you in advance for your assistance and consideration.

Sincerely,

Hugh Williamson
Director, Europe and Central Asia Division
Human Rights Watch
In recent years, the Kyrgyz government has taken steps to better protect the rights of people with disabilities, including ratifying the United Nations Convention on the Rights of Persons with Disabilities in 2019. Despite these steps, people with disabilities in Kyrgyzstan still face discrimination and segregation. This starts at an early age: government bodies and policies formally or informally block children from enrolling in mainstream schools. Instead, they are isolated and educated at home, segregated in special schools, or placed in a residential institution far from their communities.

Insisting on Inclusion documents how the government of Kyrgyzstan has failed to protect children with disabilities living in state residential institutions and schools. Approximately 3,000 children with disabilities live in state institutions and can face neglect, discrimination, and inappropriate medical treatment. Despite a government pledge to close many state residential institutions for children, the number of children in institutions has actually increased in recent years.

The report also documents the numerous barriers to education children with disabilities face when attempting to access inclusive education in the communities where they live. State commissions tasked with evaluating children with disabilities actually block their enrollment in mainstream schools, school infrastructure is largely inaccessible, and schools do not provide children with supports to facilitate their learning in inclusive environments. Children with disabilities and their parents often lack access to adequate information and resources to make informed decisions about education.

Human Rights Watch urges the Kyrgyz government to guarantee quality, inclusive education for children with disabilities. Kyrgyzstan should implement a time-bound plan to end institutionalization that includes children with disabilities on an equal basis with other children. As part of this policy, the government should provide community-based support services to children with disabilities and their families, including access to schools in their communities.