

LEGENDS:

OUT OF SIGHT

Situation of mentally disabled children in Russia

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Photo 01 -

A teenager with multiple disabilities is outlined against the light in a room in the wing for "bedridden" patients at the Serguei Possad care home. This institution is home to 270 children, 80 of them housed in this wing.



Photo 02 -

Two carers explain to Macha (multiple disabilities) how to wash her hands properly.



Photo 03 -

A carer at the CPP (Centre for educational therapy, Moscow) covers her ears to block the cries of Sacha, a four-and-a-half-year-old autistic child. His mum comments "there's still a lot of pressure in maternity wards to give up children like this, but these days parents' attitudes have changed and nobody can force us to abandon our child!"



Photo 04 -

Andrei has four children, including Varia (right), who is 10 and suffers from cerebral palsy. He also runs the carpentry workshop for young adults with mental disabilities at CCP (Centre for educational therapy, Moscow). He says that when he discovered his daughter was disabled he "had to learn to see life differently, to build my life around her. I had to accept that we must live with it, there would be no miracles. "Just give up, you'll never get anywhere with her" was the only message we ever got from the public institutions. "



Photo 05 -

Part of the medical team at the Sergei Posad care home. Recently, access to state-run care homes has once again become very restricted. We managed to visit one in Sergei Posad, a town 70 km from Moscow. This medium-sized residential institution (300 children) is considered to offer a service of "average" quality: neither the worst nor the best in Russia. Our visit allowed us to see the living conditions of these disabled children, who have mostly been abandoned by their families. We worked with children classed as "bedridden", i.e. suffering from multiple disabilities.



Photo 06 -

Portrait of a young boy with multiple disabilities in a bedroom in the Sergei Posad care home's "bedridden" wing. The children can be up to 14 per room.



Photo 07 -

Natalia Panotchkina, head doctor of the "bedridden" wing of the Sergei Posad care home, with Micah, a five-year-old suffering from hydrocephalus.



Photo 08 -

Portrait of Guisman, a little boy of nine, who has just been put into a straitjacket so prevent him from injuring himself.



Photo 09 -

Maxime, 10 years old, has Down's syndrome and spends all day rocking himself back and forth.



Photo 10 -

Alexandra, 17 years old. When she comes of age she will be moved from the care home into an adult psychiatric hospital.



Photo 11 - Leonid Mogilevsky carries Genia (14 years old) to his new bed in his new bedroom.



Photo 12 - Ten-year-old Anastasia does not want to go to bed.



Photo 13 - Anastasia, 10 years old. It is essential for the children to spend time in an upright position ("verticalisation") for the healthy development of their bodies. This helps establish a robust digestive system, develops the muscles of the legs and feet, and, thanks to the discovery of horizontal vision, allows them to socialize more easily.



Photo 14 - Andrei is 17. When he comes of age he will leave this care home to live in a psychiatric hospital with other adult patients.



Photo 15 - Lying on the carpet in the playroom, Alina (eight years old) waits for someone to come and take care of her. In spite of improvements to the care routine and an increase in staff numbers, half of the care home's bedridden children have no physical activity, which means they are not "verticalized", spending 24 hours a day staring at the ceiling.



Photo 16 - Svetlana Chtarkova, mother of Ivan, a three-year-old with multiple disabilities. This young woman is very active in the parents' group "way of the world", and writes a popular blog about disability issues.



Photo 17 - Rehearsing a play with young people with mental disabilities. Igor Nieoupokoiev, the director, brings out the artistic power of these amateur actors, showing how much their sensitivity could benefit society.



Photo 18 - Drama rehearsal with young people with mental disabilities. "Oh, if only you could accept a little of my madness! Go on - accept me!"



Photo 19 - After a drama rehearsal, a grandmother kisses her grandson, who has Down's syndrome.



Photo 20 - Ilya (13 years old) having an epileptic fit. When he was born doctors only gave him a few days to live, yet he survived. Although today he suffers from multiple disabilities, he has learnt against all odds to walk, to feed himself and to communicate a little with those around him.



Photo 21 - 13-year-old Ilya, and his sister Alla, 17.



Photo 22 - Close-up of Ilya's hands just after a severe epileptic seizure.



Photo 23 - Portrait of Sergei Koloskov and his wife, with their 21-year-old daughter, Vera. An important figure in the struggle for respect for disabled people in Russia, Sergei Koloskov is a trained musician and an artist at heart. He embarked on this fight after Vera, his second daughter, was born with Down's syndrome in 1989. He and his wife were the first to dare ask to be photographed with their daughter, to break the taboo of disability. Talking of his discovery of the care home system in the 1990s, he says "there was no way to ignore such suffering." It is in part thanks to him that the first images of these care homes were shown around the world ... and that things have now begun to change.