

case

In August 2008, six year old Kristina was placed into a psycho-neurological care home for children with multiple developmental disabilities, thereby separating her from her twin sister with whom she had lived since birth. When they were three years old, an American couple had intended to adopt both girls, but the local guardianship board instead awarded parental rights to their aunt. The sisters were removed from their aunt's care three years later due to neglect and placed in a hospital awaiting assessment of their needs by a local PMPK board. Kristina's sister was assigned to a boarding school for children with visual impairments and then taken in by a foster family, which was quite a rare event for a disabled child. However, Kristina was placed by the PMPK in a psycho-neurological care home due to her blindness and perceived IQ levels. The emotional shock of being separated from her sister was aggravated by the inhumane conditions at the setting such that she refused to speak, move or eat. The isolated location of the care home prevented regular visits by volunteers who had cared for Kristina and her sister in hospital and they were shocked at her total dependence on external care when they visited after several months. A public campaign to find a family placement for Kristina attracted significant attention in the media and from many key figures in Russian child protection. A later public investigation found high cases of child death as well as sexual violence in the care home.

Procedures

The special psycho-medical-pedagogical commissions [*psikhologo-mediko-pedagogicheskaya komissiya*] that assess disabled children and create 'rehabilitation plans' for them. These organisations are known in Russia by their abbreviation PMPK. Without the official disability certificate [*spravka* in Russian] issued by these commissions, parents are unable to receive financial, medical and welfare support to support their children, thus giving the PMPK a power imbalance over applicants and their families.

The PMPK operate at local, regional and national levels and may comprise defectologists (special educators), psychiatrists, psychologists, paediatric doctors, nurses, social pedagogues and speech therapists, although there is generally a medical dominance. Following submission of various medical documents, psychiatric assessments and school reports, children are tested by the commissions, parents are questioned and a decision made about whether to assign one of **eight** categories of disability. In relation to mental disability, the PMPK have abandoned the derogatory Soviet-era classifications 'idiot,' 'imbecile' and 'debile' and are now officially banned from pronouncing a child 'uneducable' (see Sutton 1980 for the original meaning and use of these terms). Nonetheless, mental disability is still discussed as 'mental retardation' or 'deviation in cognitive development' (*umstvennaya otstalost' or otklonenie v umstvennom razvitii*).

Discourses of defectology

Defectology was the field of Soviet pedagogy focused on work with disabled children akin to 'special education' in some other countries. In Foucauldian terms, it represents the professional 'gaze' and interpretation of mental disability that regulated children's lives and support for them. Today the discipline is sometimes known as 'correctional pedagogy' in Russia, but its ethos and content reflect considerable continuity from the late Soviet period. Definitions, diagnostics and care procedures for Russian children with mental and psychiatric disability have thus changed very little from the late 1960s and early 1970s, in contrast to

incremental reforms around physically disabled children (Thomson 2002; Iarskaia-Smirnova and Romanov 2007).

Although Soviet psychology, pedagogy and related disciplines were characterised by remarkable creativity, experimentation and humanism in the 1920s (e.g. Sandomirskaja 2008), later conservatism and control in the political sphere meant that state approaches to disability grew increasingly punitive and segregationist. The discipline of pedology combining psychology and pedagogy was banned and in 1936 as defectology abandoned its initially humanist ideas rooted in Vygotskian psychology. It became highly focused on identifying and treating ‘deviations’ and ‘abnormalities’ in children, thus promoting the normalising and segregationist tendencies that Foucault identified in Western psychiatry and medicine. Defectology identified eight different types of childhood disability with specialised research institutes, rehabilitation centres and schools focused on work with a particular ‘category’ of disabled child. Our focus is mental disability in children, which was termed ‘mental retardation’ [*umstvenno otstalost’* in Russian] or ‘oligophrenia.’ We are also concerned about the children who would have been labelled as ‘uneducable’ [*neobuchaemyi*] and therefore seen as outside the remit of defectology, which was a branch of education.

Susanna Rubinstein’s Soviet-era textbook *The psychology of a mentally retarded pupil* provides insight into the language and construction of childhood mental disability in the Soviet Union.¹ The publication was first published in 1970 and revised several times during the Soviet Union and remains a highly influential text used by many special educators, correctional pedagogues and defectologists in Russia today.² Rubinstein used her experience in the Ministry of Health’s patho-psychology research laboratory to recommend particular approaches and techniques for mentally disabled children. The main tenet of defectology is that mentally disabled children fundamentally differ to non-disabled children due to their different brain development:

The psyche of a mentally retarded [‘oligophrenic’] child is completely different to that of a normal child ... immature higher intellectual processes in combination with extremely rigid behaviour create ... a distinctive type of mental development (Rubinstein 1986: 23).

These assumptions meant that mentally disabled children were regarded as emotionally and intellectually ‘primitive.’ Rubinstein wrote that ‘many mentally retarded children share this specific way of thinking to a larger or lesser degree. The experiences of a mentally retarded child are more primitive, only feeling pleasure or displeasure, and having almost no subtle differentiated shades of experience’ (1986: 74). Defectology suggested that children’s mental development determined their other competences: ‘mentally retarded children start comparatively late to understand issues of social behaviour, morals and ethics due to their undeveloped thinking, weak grasp of general concepts and patterns’ (Rubinstein 1986: 72).

The upshot of such thinking was an emphasis in defectology on the key roles of teachers and special surroundings to develop children’s mental abilities. As Rubinstein’s textbook stated, ‘continuous and relentless supervision and control by teachers is the main thing needed by children ... in order to prevent bad influences and habits’ (1986: 56). Defectology conformed to ideological aims to hide disability and other ‘social problems’ from broader society by

¹ A full copy of the 1986 version of Rubinstein’s book is available in Russian at http://cl.rushkolnik.ru/tw_files2/urls_79/11/d-10450/7z-docs/1.pdf [accessed 21 June 2013]

² A Youtube video of a conference at Moscow City Psychological-Pedagogical University on what would have been Susanna Rubinstein’s 100th birthday can be found at <http://www.youtube.com/watch?v=otQB8rUbORE> [accessed 21 June 2013]

recommending a system of residential institutions separate from mainstream society as the most effective and also most humane environment for work with disabled children. Even liberal defectologists in Russia who challenged some aspects of Rubinstein's thinking described the ideal setting for disabled children as 'a children's home, school, a small village with houses and a club, where blind-deaf people of all ages will live. They will communicate with each other by touch and the help of special equipment. Such conditions for communication do not exist in standard schools and houses' (Serikkalieva et al 1978: 13). Again, the preoccupation with cognitive achievement undermined other potential goals of education that could have facilitated a critique of isolation and segregation.

Within their residential institutions, teachers and carers were supposed to use control and correction to educate and raise children: 'in a strict regime, children can behave properly. Without such a regime, they easily acquire bad habits. Idleness affects them especially badly whilst an organised regime full of work, sport and games is beneficial' (Rubinstein 1986: 57). This focus on cognitive development and 'proper' conduct instead of communication, intellectual development and emotional well-being meant that defectology had very little basis in human rights or inclusive approaches to disability. The general aim was to improve individual functioning in the hope that children would then be classified as non-disabled or with a milder disability – rather than to encourage integration into society.

Ultimately, defectology had a narrow, utilitarian focus on mental development. Perceived cognitive ability was the key criterion for differentiating children and focus of professional support. The discipline promoted the idea that only trained professionals could work with 'defective' children; mainstream teachers and families were excluded from involvement with disabled children and made to feel untrained and unprepared to work with them. Indeed, the Soviet welfare system for disabled children, chiefly special commissions for assessing disability and residential institutions, was founded on defectological principles. The next section considers how discourses of defectology became concretised in institutional practices and procedures with very real consequences for mentally disabled children's lives and well-being.