

## Changing Attitudes to Disability in Russia, Ukraine and Central Asia

### The BEARR Trust Annual Conference 2008

Held for the first time in BEARR's new premises in CAN-Mezzanine in Southwark, the Annual Conference revisited themes that have been touched on several times since the conferences began in the early 1990s. What has changed since then? Has progress been made? Appropriately, two of our speakers were wheelchair users who had flown in from Russia and Kazakhstan respectively, and they were able to give the delegates first-hand accounts of their experiences and of the campaigns they are managing.

But rather than begin in the 1990s, we went back initially to the early 20<sup>th</sup> century, as **Dr Elena Iarskaia-Smirnova** of Saratov State Technical University sketched out **The Historical and Sociological Background** to attitudes to disability, and **Michael Rasell** of Birmingham University examined the evolution of **Disability Law and Policy**.

Iarskaia-Smirnova traced the dominant themes in the Soviet approach to disability, the most persistent of which was 'who does not work does not eat'. This maxim resurfaced explicitly at several points throughout the 20<sup>th</sup> century, and was implicit in insurance-based healthcare for workers only, and the notion of 'rational management' of disability in relation to a person's capacity to work. Typical of this approach was the creation, as part of the New Economic Policy in the 1920s, of large associations such as the 'Electric Engine Enterprise of the Blind' to provide work opportunities for the disabled.

Paradoxically, the development of 'rational management' of disability ultimately led to the marginalisation and exclusion from work of some disabled people. The activity of 'experts' in expanding and refining definitions of disability led to the creation, in 1929 (two years into the first Five Year Plan), of the Scientific Institute of Defectology. Some forms of disability were classified as capable of work; others were excluded. As the command economy developed, the State sought tighter control over cooperatives of disabled workers. The establishment of nursing homes, advertised as a benefit of socialism, often led to the removal of disabled people to isolated converted monasteries.

The 1950s saw the emergence of the idea that disabled people could receive a pension and not work at all. State control and isolating forms of care provision increased, so that by the 1960s there was little chance that a disabled person could have economic independence. By the 1980s the normative image of a disabled person was of a pensioner, not an enthusiastic worker. It is worth saying at this point that when Iarskaia-Smirnova spoke of "images", she was able to select from a fascinating archive of information and propaganda posters, many of which the delegates had not seen before.

*The BEARR Trust is grateful for the support of CEELBAS in preparing the conference, and for the sponsorship of Q'straint, manufacturers of safety belts for wheelchair users.*

But there was and still is ambiguity both in official discourse and in public attitudes. ‘Who does not work does not eat’ was still appearing on posters in the 1960s and again in the 1980s. A famous 1960s comedy film mocked the system and portrayed the pensioned disabled as spongers and parasites. A survey carried out only this year revealed a common attitude that the disabled “are a burden to society”.

There were other themes too. Military invalidity was prominent after each World War. In theory, disabled soldiers received the biggest pensions and privileges. In reality, these were not always delivered. An ideological strand emerged after the 1917 Revolution, which excluded from help all the ‘socially alien elements’ such as White Army supporters, kulaks, manufacturers and landowners. A further influence on attitudes to disability was (and is) deep-rooted folklore that regarded disability as a mark of personal guilt, and a just reason for exclusion.

Iarskaia-Smirnova gave credit to the Soviet Union’s characteristic “big experiments, big challenges, and big mistakes”. The pioneer who first proposed that blind and deaf people were not incapable of learning was imprisoned, but eventually a school was established and the first students graduated in 1971. Meanwhile the Soviet population mastered the skills of using official or unofficial channels to criticise the social environment. While the State continued to present itself as a rich and responsible provider throughout the ‘Zastoi’ (stagnation) years of the 1980s, a sense of rebellion and liberation was revealing itself in underground literature, until the idea of ‘rights’ reached the light in the years of post-Soviet freedom. At this point, we begin to see the parents of disabled children start to challenge openly the dubious classifications and practices of the ‘experts’.

**Michael Rasell** built on this background by explaining how much the framework for disability policy in Russia and the CIS is still conditioned by the Soviet past. The international definition of disability, enshrined in the 2006 UN Convention on the Rights of Persons with Disabilities, is based on a ‘social model’ that puts discriminatory conditions in society at the heart of definitions of disability. The social model aims for society to adjust to promote the inclusion and participation of the disabled, as well as giving medical support. The Soviet and post-Soviet framework is, in contrast, a ‘medical model’ in which the most significant feature is the provision of medical help to restore a disabled person’s ability to adapt to society, and in particular to work. This medical model is paternalistic, institutionalised, limiting of disabled people (a consequence of the ‘science’ of Defectology), and gives priority to soldiers and workers over children. Its outward manifestations are inaccessible housing, transport and public buildings, and, in social attitudes, the perpetuation of stigma and misunderstanding.

Rasell posed the question: can a rights-based approach to disability work in Russia? His examination of post-Soviet legislation – the 1993 Constitution; the 1995 Law on Disability – showed the emergence of the language of rights, such as the right to

education and the right to work. However, these laws were declarative, with no provision made for implementation. Firms pay fines rather than comply with employment law. Only 15% of disabled adults work in Russia, compared with 40-50% in the US. The power of expert medico-social commissions persists, working without representation of the disabled and with little family consultation, and so tending to perpetuate traditional definitions of and approaches to disability. The study of Defectology by trainee teachers has morphed into the new 'Correctional Teaching', which is a separate strand of teacher training and creates a barrier against inclusive education.

**Tony Longrigg**, BEARR's new Chairman, was struck by the perverse influence exercised by the Ministry of Finance, responsible for the controversial 'Monetisation' policy of 2005 (which effectively withdrew much practical help from disabled people) and the cancellation of tax breaks for the disabled employed. The Ministry of Finance also has a powerful indirect influence through its control of resources to NGOs (disbursed through State-sponsored competitions), which are tending to make NGOs more bureaucratic and to function as extensions of ministries.

Although current policies have not yet broken away from the Soviet idea of the disabled as passive recipients of State aid, there are some positive trends such as the development of new NGOs and the opening of rehabilitation centres. **Chris Goodey** of the Centre for Studies in Inclusive Education noted some very positive attitudes in Moscow towards children with learning difficulties. Iarskaia-Smirnova said that parents of disabled children were the strongest campaigners for progressive policies, and were effective in pressurising local authorities. The Centre for Curative Pedagogics in Moscow is campaigning for disabled rights and is challenging the power of expert commissions. However, Moscow is ahead of other administrations in Russia, and overall, grass-roots efforts have not yet translated into top-down policy change.

Interestingly, the most progressive former Soviet country in terms of legislation is Turkmenistan, which has just ratified a law on disability that comes closest to the 2006 UN Convention. But in general, as Rasell concluded, even where internationally accepted principles such as independence and inclusion are reflected in the wording of legislation, the devil in the detail limits effective implementation.

The next three sessions of the conference enabled comparisons to be made between Russia, Ukraine and Kazakhstan.

Within **Russia**, the experiences of **Denise Roza** and **Natalya Prisetskaya**, respectively Director and Programme Manager of Perspektiva in Moscow, and **Tanya Buynovskaya**, Programme and Partnerships Manager at Healthprom, contrasted activity in Moscow and the situation in more distant provinces such as Altai.

In Moscow, the city government is giving such large sums to companies to promote the employment of disabled people that Rosa wondered whether it was counter-productive. She felt that employment law needed further reform to get companies to act in the real best interests of the disabled. She pointed out that many disabled people are ill prepared

for work, because they lack education or went through the inadequate Home School Programme, and as a result are at risk of being exploited by companies who employ them.

Perspektiva is part of a network of NGOs that promote the key principles of the social model of disability: human rights and independent living. The case for inclusive schooling is made by a coalition called 'Independent Living Network Inclusive Education for All'. A programme called 'Path to a Career' aims to increase mainstream employment for the disabled – but so far, its activities are mainly confined to Moscow. **Francis Callaway**, BEARR Trustee, suggested that foreign companies might have a better approach to employing the disabled, and indeed companies that Perspektiva look to for leadership include KPMG, Nike, Johnson and Johnson, Renaissance Capital and Citibank.

Perspektiva also organises events, such as the Disability Film Festival, to raise awareness, and trains other NGOs in media collaboration. The power of the media was demonstrated by Prisetkaya herself, whose quick reaction when S7 Airlines refused to let her board a plane with her wheelchair led to massive media coverage, support from government officials and the public, and offers of help and new partnerships from legal firms.

Far away in the Altai region, Healthprom tackled the problems faced by families with disabled children in remote rural areas, and were ultimately successful in setting up two day care centres for 'uneducable' multiply disabled children. Buynovskaya emphasised how much effort had to go into changing attitudes, in particular training conservative doctors to talk to parents and the children, and to work with other professionals. The other problem was dealing with the local government after appointees took the place of elected officials ("the new person comes with new rules") but one of the project's successes was the development of Healthprom's partner, 'Vozrazhdenie' (Revival) to the stage where they could work both alone and in collaboration with the government.

Concerning **Ukraine**, **Mykola Swarnyk**, Associate Professor at Lviv National Polytechnic University, talked about the two organisations he had founded: Nadiya Association for Children with Cerebral Palsy, and Dzherelo Children's Rehabilitation Centre. Swarnyk has created a strong national organisation uniting over 70 local groups of parents and medical professionals in order to provide services and to lobby for the rights of people with intellectual disabilities. In the 21 years since the birth of his own son (who is a wheelchair user with mental retardation), much has improved. There are now some community-based services providing early intervention and physical rehabilitation. Swarnyk takes some of the credit for introducing three new professions into Ukraine: physical therapists, social workers and special needs teachers. However, the profession of occupational therapist is not yet established. Also, Swarnyk is still campaigning (and would like to collaborate with Western professionals) to introduce further education for more severely handicapped people. New building codes are starting to improve (patchily) access, and Swarnyk is delighted by recent publicity coups that are helping to change attitudes to the disabled. He is encouraged by the growing confidence

of parents in organising events, lobbying, and getting elected to local councils, as he himself has done.

**Katerina Kolchenko**, Prorector of the Open International University of Human Development in Kyiv, described her shock when she visited England in 1995 on a British Council programme, and saw disabled children in mainstream nurseries and schools. Ukraine had lagged Russia in giving disabled students access to higher education (not achieved in Ukraine until 1999). Yet only nine years after Kolchenko's epiphany, she had set up, without public funds, the Open University of Human Development, which now has 47,000 students, of whom 1,800 are disabled. It is the first fully accessible university campus in Ukraine, and is trying to overcome the acknowledged difficulties students and lecturers have in adapting to each other in order to pursue an inclusive model of higher education. There are 13 institutes, 10 branches, 16 regional and 110 local centres of distance learning throughout Ukraine. The aim is to provide full access and to enable students to study from where they live, in the most flexible way possible.

**Tony Wolstenholme** of Child Health International said that the possibilities opened up by new technologies for the education of the disabled merited cooperation between institutions in the UK that already make use of them, and Ukraine.

In **Kazakhstan**, **Lyazzat Kaltayeva** chairs SHYRAK Disabled Women's Association in Almaty – disabled women suffer threefold discrimination on account of their gender, their disability, and often their poverty. NGOs like SHYRAK started to emerge when the position of disabled people deteriorated during the crisis years of 1992-6, and now that the economy has stabilised, they are becoming involved in government decision-making. There is now greater awareness of the social model of disability, and SHYRAK is encouraging greater inclusion and participation for women in both education and employment.

Both Kaltayeva and **Jonathan Watkins**, Project Manager at Healthprom, noted cultural differences between the different Central Asian countries, despite their common Soviet heritage and language. The more stable and prosperous countries have a more liberal approach to disability, in contrast to those that have suffered recent violent conflict through civil war (Tajikistan) or revolution (Kyrghistan). Watkins, who had been working with an NGO and the Dushanbe city authorities to provide more home support and reduce intake into baby houses, discovered greater extremes of social exclusion in Tajikistan than he had encountered working even in the rural Altai in Russia.

The common theme of overcoming the destructive work of medical commissions in fixing people in defined categories of disability emerged also in Central Asia. Some progress has been made: 'ineducable' rulings are no longer made, and Watkins hoped that the commissions could become a means of facilitating access to education. Kaltayeva was concerned that, while understanding of the social model of disability with its underpinnings of rights and inclusion was increasing, it could be threatened by the spread of Islam, which emphasises charity rather than rights.

**Charles Buxton**, the Central Asian representative for INTRAC (International NGO Training and Research Centre), looked at the prospects for disability NGOs in Central Asia to attract funds from international donors. Donors are now trying to limit their risks by giving funding to governments rather than NGO-based programmes, although NGOs that deal with disability have an advantage in often having a strong membership base and therefore being perceived as close to their communities.

Like Kaltayeva and Watkins, Buxton observed different country contexts throughout Central Asia, but he drew some general conclusions: an encouraging willingness to look at outside experience and adopt new laws, but marred by poor implementation and professional incompetence and the persistent lack of disabled representation. More money is coming from business, but poverty still means that many families cannot afford to look after the disabled at home – institutions such as baby houses will have to continue for some time, and a system of fostering is a more distant prospect.

In the final session, the conference focussed again on NGOs and how they can influence attitudes to disability in Russia, Ukraine and Kazakhstan. **Charles Walker** of Oxford University said that NGOs in the region had made good progress in moving thinking about disability away from a medical model and towards a social model. There had been some setbacks, such as the Monetisation policy in Russia, and there was still doubt about how to change the attitudes of doctors on medical commissions. NGOs needed to be more visible.

**Roza** recommended working only with receptive groups and not wasting time on those whose attitudes would never change. She thought that more should be done to bring in best practice from NGOs elsewhere in order to achieve “the missing vision”. **Rasell** believed that training social workers was important. Because decisions are not made in a multi-agency framework, it was important to instil the right attitude in at least one person in each area.

Some confusion emerged about whether NGOs should campaign for the right to remove certificates of invalidity from people who were capable of work, with **Wolstenholme** and **Prisetskaya** pointing out that some people sought more serious classifications of invalidity in order to get a higher pension. A discussion on the use of language was similarly inconclusive: **Kaltayeva** had earlier drawn attention to the difficulty of finding appropriate terminology for invalidity that was not clumsy, and Roza believed that NGOs had a role in finding better, non-offensive terms, or in trying to remove the stigma from otherwise acceptable words. **Kolchenko**, in contrast, thought that language took second place to practical action to improve lives.

**Jo Lucas** of Kastanja Consulting, who had worked with Mykola Swarnyck in Ukraine, raised the issue of corruption among the directors of baby houses and internats – NGOs should question what the directors did with the government funds they received.

Thanking the speakers at the close of the conference, **Tony Longrigg** commented on the superb quality of the presentations and contributions, all the more impressive given that

several speakers were not using their first language. He reminded delegates that The BEARR Trust would run its Small Grants Scheme again in 2009, and welcomed project proposals.

*Nicola Ramsden, BEARR Trustee*