

Disabled often among the 'poorest of poor'

An Oscar-winning Spanish film about a quadriplegic may raise awareness about disability, but much more is needed to galvanize international efforts to support people with disabilities, 80% of whom live in poor countries

"My first group came from the United States. When I met them at the airport I was stunned — there were three people in wheelchairs," Yelena Popova, a Moscow tourist guide, still raises her eyebrows in amazement as she remembers her experience eight years ago.

"I thought to myself: 'God, I don't think I have seen that many people in wheelchairs in Moscow in my entire life. What am I going to do with them?'"

Yelena is a young, well-educated and liberal-minded person. Her bewilderment at the fact that disabled people go on tourist trips just like anyone else is a stark reminder of the contrast in attitudes towards people with disabilities in developed and developing countries.

Some 600 million people in the world experience disabilities of various kinds and the vast majority, or 80%, of them live in low-income countries, according to WHO. More often than not they are among the poorest of the poor, forced to spend their lives struggling to survive in a world where finding food and shelter is a challenge.

Their functional limitations lead to social exclusion, unequal rights and limited opportunities.

Despite collective and private efforts to prevent disability, the number of disabled people on the planet is on the rise, boosted by malnutrition, non-infectious and congenital diseases, war injuries, HIV/AIDS, chronic conditions, substance abuse and environmental damage. Population growth and life-prolonging medical advances also account for much of the increase.

People with mobility-related impairments are usually the most visible among the disabled but many activists believe that mental health conditions are by far the most likely to lead to social exclusion.

"These people need help most," said Tatyana Kirillova, a disability activist in the central Russian city of Volgograd and herself the mother of two children with severe mobility-related and mental impairments. "Doctors put a big cross on them right from the start. Maternity nurses go out of their way to

convince mothers to give up babies if they have Down syndrome."

While the trend in wealthier countries is towards more community-based care, many low-income states still try to lock up people with disabilities at home or in specialized institutions and these people are often regarded as second-class citizens who can hardly hope for more than to be the passive recipients of aid.

The Russian Federation, a middle-income country riding the tide of massive oil revenues, is just one example of how far many societies still have to go to match their good intentions to ease the plight of the disabled with deeds.

The country has a first-rate disability law guaranteeing social security assistance to people with disabilities as well as unrestricted access to public transportation, government buildings, sports activities and a free education.

In reality, for a person in a wheelchair even leaving the house often proves a daunting task, as most older buildings in Russian cities and towns either have no lift or their lifts are too narrow for a wheelchair.

In a recent case that ended in court, activists had to mount a full-scale legal battle to secure permission for a five-year-old girl with Down syndrome in a town near Moscow to be accepted into a nursery.

According to official figures, of some 650 000 disabled children in the Russian Federation only about 185 000 receive general or special education. Over 70% of disabled children in the country receive little or no formal education.

The situation is similar in most low and middle-income countries. To address the lack of services for the disabled, the United Nations has launched an offensive to galvanize governments and grass roots into action.

In 1993, the General Assembly adopted the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities. The rules, written from a human rights perspective, offer guidelines on how countries can create more equitable conditions

for people with disabilities. Although not compulsory, they implied that states should take a strong moral and political commitment to take action.

"The rules have contributed enormously to the development of legislation and to the confirmation and strengthening of disabled people's organizations (DPOs)," Dr Federico Montero, Disability and Rehabilitation Coordinator with WHO in Geneva, told the *Bulletin*. "These elements have also played a key role in promoting and improving participation and inclusion of persons with disabilities in many societal activities."

Number one on the rules list is raising awareness. Last February the campaign received a surprise high-profile boost when the US Academy awarded its Oscar for the best foreign film to *The Sea Inside*, the story of a quadriplegic Spanish activist fighting for the right to die after 30 years of immobility.

The film's success is certain to bring the disability issue to the forefront of public debate. That debate may in turn help the United Nations implement its second key strategy for promoting the rights of the disabled, community-based rehabilitation (CBR).

At the heart of CBR lies the notion that disabled people should achieve their rights within rather than outside their communities and societies.

Over the years CBR has evolved from a medical model to a more holistic one, putting a major emphasis on human rights and inclusion. Though much work still needs to be done to ensure CBR's success, studies so far indicate that it has already had a positive impact on the lives of those involved.

CBR programmes have helped people with disabilities to become more visible and shown that they can contribute to family and community life. They have also had a positive impact on the self-reliance of many children and adults with disabilities, especially through training in daily living skills.

As one CBR programme participant in Africa said: "Previously, I felt very inferior but after I joined the CBR programme ... I have been able to overcome that feeling ... I can now assess myself with others and say that I can perform certain activities and tasks better than the able-bodied." ■

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