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## **Problems and Perspectives of Disability Policy in Russia: The Move from Paternalism towards Disability Rights?**

The construction of disability policy in the USSR included an extensive social welfare system, pensions for disabled people, free universal health and social care services, free and environmental inaccessibility of education. The Soviet State organized good disability care and general social security for disabled people, to all of whom the state guaranteed a good quality of financial safety through disability pensions and various social programmes. Legal protection was based on constitutional provisions. However disabled people were typically seen as objects of pity or compassion who required charity and services. This disability policy was paternalistic, segregative, and promoted the social exclusion of disabled people. But with the end of the Soviet era the period of paternalism in disability policy was also coming to an end.

Since 1991, the collapse of the USSR has brought a number of fundamental changes for disability policy in Russia. Disabled people have met with unexpected consequences of political and economic reform in Russia. The concept of universal social support, based on the principles of solidarity, is being transformed into a liberal welfare policy. As a result of changes in Russian social policy, the social security of disabled people has reduced. From a sociological point of view, the social situation of disabled could be described in term of anomie. The transition to a market economy has brought a number of basic changes in disability policy.

These changes affect the financial well-being and status of disabled people profoundly. Unfortunately our society is a society of war. There are a lot of disabled after Afganistan and after Chechnia wars. Ana after 1991 War Disability has taken on new significance and become the main priority in Russian disability policy. The social and economic well-being of disabled war veterans had been better than that of other groups, while most Russian disabled people confronted the task of survival. They had very low levels of pensions and benefits. It was hard reality for many disabled people. Also during the Yeltzin's period severe economic and political crises, a reduction of social protection, increasing unemployment – all exerted a negative influence upon the chances for integration and full participation of disabled people in social life.

The changes during recent years in Russia have occurred very quickly. The number of disabled people has increased. In 1989 there are 7 millions of disabled people in Russia. In 1999 we have 9 millions of disabled. The demand for social service grew rapidly. As a result, more disabled people came into contact with social services. This required more and more money, but the state was unable to deliver it. This is the model of relations between the state and disabled people which has been used for the last 10-12 years. Hopes for successful and rapid reforms have dissipated and social inequality has become more apparent. Today, the important issues debated in disability policy are concerned with re-defining disability, with low pensions for disabled, with the promotion of inclusive education for disabled children, with the social mobilization of the oppressed and with the mobilization of the disabled people's movement.

The implementation of disability rights depends on federal, regional and local programmes of social help for disabled people. The federal social programmes became the basic tool for disability policy, but it is very difficult to say whether they are efficient or not. Such data are simply not simply published. There are many disability programmes now (for example, such federal programmes as "Social Support for Disabled", "Organizing Accessible Environment for Disabled", "Social protection for war disabled") all of which include different bodies of management.

Successful implementation requires a process of flexible management coordination and this is the major administrative task facing the Russian state. Another task for the state is to create a special national employment program for disabled people – as the rate of employment for disabled people in Russia is still only 10%.

Positive changes for Russian disabled people during this period resulted in:

- a) The development of a market sector [but some people not see this as +]
- b) The development of NGOs of disabled and for disabled
- c) The development of a special disability status and a state definition for disabled children.

The market, as a sector of corporate social and disability policy (second sector), exists in many forms. Besides formation of the state's budget and social insurance funds, the various branches of business create their own private systems of pensions for disability and medical insurance, as well as social infrastructure. But the diversity of social policy produces varying levels of social security for disabled people in Russia.

Nowadays we can also see the development of new institutions in civil society. The Russian Union of the Disabled People was formed more then 14 years ago and there are now many public organizations of and for disabled people in Russia. Public organizations of disabled people and charitable organizations for disabled people have the status of noncommercial and nongovernmental organizations.

Whether there is a civil society in Russia or not is a difficult question to answer, but the third sector and the disability movement do evidently exist. The number of third sector disability organizations in the Russian Federation is difficult to account for. Only 15-20% of NGO/NCO are actively in business. The importance of such social participation of disabled people is huge. The Russian disability movement strengthens the ambition of disabled people to live an independent life. It provides a powerful social base for general well-being. The “economy” of the third sector for disabled people is very specific in Russia. This type of economy deals with the task of survival and the social adaptation of low income families with disabled members. There are kitchen garden families and cooperative companies for processing and storage of their own crops.

During the communist period we had no special disability status or rights for disabled children. Disabled children were in most cases in the Soviet Union taught in special segregated schools, or brought up in special segregated children’s homes or boarding schools. Now we have a very good national programme for “Children with disabilities”. The disability status of disabled children has improved and our society discusses the possibility of inclusive and integrative education.

In 1995 the Russian Government adopted the Russian Federal Law “Concerning the Social Protection of Invalids”, which determines disability policy in the area of social protection. The goal of this disability policy is to provide equal opportunity for invalids in the realization of their civil, economic, political and other rights and freedoms. It was a very progressive piece of legislation for post-communist Russia. The type of this disability legislation legal expression of human rights, basic type - Constitutional Guaranty of Equality (paternalistic approach in disability legislation).

The dominant official definition for disability is medical definition. Invalidity is a health infringement with stable function disorder which are illness trauma consequence or defects. Invalidity adduces towards ability limit and needs for necessity of social protection.

Definition of person who is disabled – invalid. The term “invalid” means any sick person or person with impairment.

Now, the basic aims of social protection for disabled people in Russia are defined broadly – protection in rehabilitation, medical help, telecommunications, accommodation, employment, education, services, facilities, transport (including planes), sanatorium treatment and financial insurance. There is no enforcement commission but individuals may file private complaints. There are collective human **values** about discrimination and civil rights for disabled people but no civil rights tradition. The Law mentions equality of opportunity but does not mention discrimination.

The population of Russia now includes about 9 million disabled people, representing 7% of its inhabitants. These figures do not represent the total number of disabled people in Russia (probably some 15 million). Rather, they are based on the number of registered disabled people, i.e. those who acquired disability status by going through a prescribed procedure, in the course of which they were found to fulfil relevant conditions associated with Russian meaning of impaired health. There are many disabled people in Russia who have no disability status, simply because the prescribed procedure is a difficult bureaucratic one.

In Putin's era, disability policy in Russia is facing a triple set of problems:

1. First, the reduction of social protection for disabled people took place in the context of a general and progressive worsening in the standard of living, which resulted in broadening gap between rich and poor. It is impossible to overcome this gap until at least 2010, depending on the low level of pensions for disabled people. At present disabled people remain poor in our country.
2. Second, laying the burden of responsibility on local government is producing progressive inequality between the regions. In our country there are rich and poor regions, and the level of pensions received by disabled people varies from one region to another.
3. Third, many of our dominant cultural traditions and values about disability are themselves disabling. Moreover they create disabling policy responses. The experience of disabled people is invariably presented to us in terms of "personal tragedy", the impaired body and "otherness". Such values find their expression in contemporary Russian disability policy through a preoccupation with segregation, indirect discrimination, "care", exclusive education, medicalisation and individualism.

In addition there is currently no comprehensive National Disability Policy Conception for the development of programmes and services for disabled people in Russia. Furthermore there is no Anti-discrimination legislation for disabled people, to combat direct or indirect discrimination. As a result, there is no inclusive disability policy.

Is there any cause for optimism, or should the future of disabled people be viewed with skepticism? I think that the social and economic factors will create instability in Russian disability policy in the future. As a result the trust of disabled people in the state has lessened. For example, in June 2004 only 40% of disabled people approved of new Disability Legislation concerning Direct Payments for Social and Health Care Services. They feel as though they are second class citizens and, at the moment Russian disabled people have little cause for optimism.