

DISABLED YOUTH IN UKRAINE: THE GOVERNMENTAL POLICIES AND GRASSROOTS ACTIVITIES

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The article explores some acute issues of the modern Ukrainian society from the disabled youth perspective. The author gives some statistical data on the growing numbers of disabled population in Ukraine. The analysis of the Ukrainian legislation regulating the governmental policy towards the disabled youth is provided. The overall review of the main tendencies in the grassroots activities by the disabled youth organizations is also given. The author shows the biggest challenges faced by the young people with disabilities in Ukraine on all levels.

Keywords: Disabled youth, governmental policy, grassroots activities, legislation, social defense, Ukraine.

Introduction. Ukraine, as a former communist country, is overcoming quite a lot of the obstacles, common for a state in transition, on its way towards reaching the developed world standards of economic, political and socio-cultural relations. Entering the European Union, so desirable for the Ukrainian government, will hardly be possible without joining the European standards of policy making and human rights provision. For this purpose Parliament have joined the UN and EU conventions «On Human Rights» and adapted most domestic laws to their demands.

However, the present situation in Ukraine is far from the one reflected in the legislation and described in official international reports. Though general living standards have much improved since 1999, when 70 percent of the population used to live under the level of poverty [2], the socially undefended groups, such as elderly and disabled people, still remain the most marginalised and deprived categories of citizenry. The contemporary situation in the development of Ukraine is characterised by rather negative social attitudes towards disabled people who widely suffer from social exclusion which largely helps create the marginal status of the disabled and their psychological deprivation. These are «the common reasons of chronic depressions, the feeling of loneliness, closeness, hostility, oppression and indifference» [1, p. 74].

On the other hand, there is no tradition of community based rehabilitation (CBR) in Ukraine, neither the governmental bodies or Social Services have qualified personnel, sufficient funds and equipment, available to provide successful activities in this direction. Disabled persons' human rights are likely to remain just declaration partly because of lack of awareness amongst the wider society and partly as a result of general passivity of the disabled themselves.

Therefore, the **goal of this article** is to critically evaluate the existing strategies and practices in developing social policies, providing social and rehabilitative services as well as adapting human rights approach to the process of social inclusion of disabled people into the mainstream Ukrainian society.

The secondary data review. To tackle the problems of the disabled the government have been introducing the new and comprehensive social policy which define the priorities for and the ways of social rehabilitation of disabled people in Ukraine. According to the National Programme of Social

Defence of Disabled People introduced by the Cabinet of Ministers in 2003, the disabled youth is one of the oppressed and most economically disadvantaged groups of populations [1]. This situation is partly due to the substantial increase in the number of disabled people as a whole (for the period from 1994 to 2012 the number of the disabled aged 5 to 65 has grown from 2,102,400 to 3,509,500 and reached the 12% percentage of total population) [1]. Young disabled people (aged 16 to 35) constitute 24% of the disabled population in Ukraine. This figure is increasing constantly due to consequences of the Chernobyl tragedy, disturbance of genotype, bad nutrition, poor medical treatment and the military conflict in the North-East of the country [1].

Hence, young people with physical, sensory and/or mental impairments are defined as a prioritized category for economic and social rehabilitation to be carried out by the governmental bodies, non-governmental organisations (NGOs) and individuals who have appropriate rights, skills and resources to provide the social services and financial help [4].

Therefore, in 2001 Parliament have introduced the law of Ukraine «On Social Work with Children and Youth». This piece of legislation defines social rehabilitation as

«work designed to renew moral, psychical and physical health of a person as well as continuation of his/her normal social functions and behaviour (Article 1) [5].

According to this law, social rehabilitation of young disabled people is to be provided mostly by the Centres of Social Services for Youth (special establishments authorised by the state to participate in actualisation of the state policy towards the youth by means of providing social work and services to children and young people) (ibid).

Hence, declaring that social work with children and youth is based on the universally received humanistic, democratic and legal principles, the law «On Social Work with Children and Youth» defines them as follows:

- Lawfulness, fulfilment and defence of human rights;
- Differential, holistic and individual approach;
- Accessibility and confidentiality of social services;
- Responsibility of the social workers for the fulfilment of ethical and legal norms, objectives and rules of providing social services;

- Voluntary basis of receiving social services. (Article 5) [5].

The centres of social services for youth are authorised to provide social services for young disabled people guaranteed by the state, which are as follows:

- free access to sports facilities;
- free advice and support on gaining paid employment in correspondence to a disabled person's preferences, capacities, education, professional training and retraining;
- service provision in the sphere of education, culture, health care, sports, special medical services, and recreation;
- Free services for satisfaction of spiritual, cultural, esthetical, educational, remedial, recreational and other needs.

(Article 8) [5].

however, social rehabilitation of disabled children and young people is seen by the governmental agencies mainly as the process of medical correction and covers just educational rehabilitation in the mainstream boarding schools for children and young people who require social help as well as in special boarding schools and other establishments for children and young people who require correction of their physical and intellectual development. That is to say, defining the main goal of social rehabilitation of young disabled people as

«taking the complex socio-medical and rehabilitative actions in order to provide adaptation of persons with physical or mental impairments into mainstream society»

(Article 7) [5],

the state provides social rehabilitation of young disabled people in segregated educational establishments only (as they are fully financed by the state). Other support (such as juridical advice, professional training and retraining, integrated living, personal assistance, access to information and special equipment, etc.) is to be provided by the local NGOs of and for disabled people.

The main challenges. Although for the last 10 years the number of NGOs engaged with the process of social rehabilitation of young disabled people increased rapidly (from 44 in 2003 to 284 in 2014 [1]), they face a range of obstacles slowing their progress in promoting everyday activities.

The major challenge – lack of information – is faced mainly by the small local NGOs, where the level of activities does not often go higher than grassroots. They provide a set of services for disabled people in their part of the city and often may not even have information about analogous organisations acting next door. Needless to say that they suffer from being under-informed about the big social actions undertaken either by local social services, or by the larger NGOs for disabled people simply because there is no appropriate information source on such issues available to the public. Short reports about the major social events taking place both on the local and national level appear in the media only afterwards.

On the other hand, young disabled people at grassroots, being largely marginalised and forgotten except on the International Day of Disabled Persons, have no information about the disability movement within their country, neither, they are

aware of their human rights protection by international law. Older generations got used to misbelieving the authorities and the media since the Soviet time. Having no access to the internet and to material in Braille, large print or on tape, they often do not even know about the services available to them.

This situation is largely caused by two factors: unawareness of the necessity to provide information in an accessible format and by the substantial cost needed to publish materials in an alternative format. The publishing industry in Ukraine still remains one of the most underdeveloped and is mostly unprofitable. Therefore, all statistical reports are produced for internal use by the social security system alone, which also does not help intensify the disability movement within the country [2].

The second biggest challenge faced by disability activism in Ukraine is lack of finance. The economic situation in the country still remains far from stable, which appears to be the cause of great under-funding of social and welfare projects both in the state and in the private sectors. Being registered as non-profitable organisations, NGOs of disabled people have to seek the external financial sources in order to provide their day-to-day activities. In most cases the money they manage to raise is enough to pay the rent and utilities only. For this reason most NGOs are engaged with writing the projects to the development donor agencies. If a prepared project is successful in its bid, there is a good chance for the local disabled community to benefit from its implementation. However, such a scenario shares all the weaknesses and misfortunes of this scheme. Bureaucracy and writing the reports takes the lion's share of the nominal workforce's time and efforts, and the funds available under such projects are always likely to be minimal and restricted in usage. Furthermore, most of the donors are reluctant to subsidise the purchase of the office equipment or technical aids necessary to work with the disabled. That is, an NGO implementing the project cannot sustain it after the donor agency withdraws and the funding stops.

Thus, not providing the basis for NGOs' sustainability, disability related projects are hardly to be the best source of finance for non-profitable organisations of disabled people. On the other hand, disability related projects funded by Ukrainian development agencies constitute only 19 percent of the total amount of money given to the local NGOs and only 8 percent of all Ukrainian NGOs of disabled people get funding from international development agencies [3].

Furthermore, the government tries to ensure appropriate financing of their own programmes of social defence and in so doing, they strictly limit the funds available to non-governmental agencies. This literally means that local NGOs of young disabled people are likely to get no funding from either the Ministry of Labour, or local social services, or from any other governmental organisation.

Hence, this inextricable situation witnesses the third major challenge faced by many NGOs of disabled people in Ukraine – minimal partnership with the governmental agencies. Unfortunately, neither the government, nor Parliament recognise the necessity of a strong partnership

with NGOs of disabled people at grassroots. Such misunderstanding leads to the ineffectiveness of all attempts to promote the disability movement's goals, undertaken by either side. There are only two representatives of the disabled in Parliament and the government try to avoid employing disabled people at all levels. Non-disabled professionals are engaged with resolving disabled people's problems in local social services. And only small number of the disabled is involved as consultants in the process of decision- and policy-making in the social sphere [1].

On the other hand, human rights of disabled people are being proclaimed only on paper without almost any practical sequences of such statements. The governmental agencies still keep working within the medical model of disability framework. That is, the Ministry of Labour and Social Defence as well as local social services are engaged with resolving mostly «medical» issues: basic health services and food provision, minimal benefit's support, counselling and home care service provision for elderly and severely disabled individuals [6]. They do not help disabled people with legal advice on their rights protection, nor work with local authorities and service providers in terms of creating an accessible environment or providing the disabled with information in an appropriate format. These purely social issues (vitally important for so many disabled people) only recently started to appear in the media and the social services' agendas. Furthermore, governmental agencies rarely support the projects on social inclusion of disabled youth initiated by the NGOs of the disabled, however, regional social services always include the NGOs' successes in their own reports. This situation, obviously, does not help build strong partnership relations and really harms the promotion of disability activism.

Another crucially important obstacle in the way of furthering disabled people's self-emancipation in Ukraine is the lack of human rights awareness which prevails amongst disabled individuals. From my own experience I know how hard it is to involve the disabled in the disability movement or even in activities intended to benefit themselves and their families in the longer term. Living below the poverty line and socialising mainly amongst their own disabled community, they are not aware of the alternative living styles and social attitudes towards the disabled existing in the developed countries. Only the disabled youth, not being influenced by the Soviet proverb «initiative is always punished», willingly participates in the disabled people's rights movement. Having wider access to higher education and feeling more freedom in coping with modern technology, young disabled people are more famil-

iar with the western practices of treating the disabled and quality of services available to them.

On the other hand, psychological factors also play an important role in forming unawareness of their rights and unwillingness to undertake any practical actions for further self-emancipation and provoking the social change amongst the disabled populations themselves, let alone the mainstream society. Lowered self-esteem obtained by the majority of disabled people as a result of many years spent in the system of segregated education, employment and living (it was a common and often the only option for the disabled in the Soviet Union) leads to the general indifference, passiveness and reluctance to support any public action no matter how useful and beneficial it might be for the whole disabled community. Therefore, substantial educative work undertaken by the development agencies is required in order to formulate an active living position, self-respect and self-reliance amongst disabled people at grassroots.

Conclusion. To sum up, disabled youth is one of the oppressed and most economically disadvantaged groups of populations in Ukraine. The medical model of disability still remains dominant both in legislation and in social attitudes. Furthermore, although the disability movement, led by young disabled people, is coming to force, it faces four major challenges: lack of information (neither development agencies, nor the public have access to the statistical data on disability related issues); lack of sufficient funding (especially for local NGOs which promote the social model of disability implementation at grassroots); lack of a strong partnership with the government (being engaged with resolving the same problems, governmental and non-governmental organisations mainly ignore each other's resources and good practices); and lack of awareness of their human rights which prevents the disabled population from wider involvement in organised public and legal action in order to support the change of social attitudes towards the disabled and to ensure their place within mainstream society.

Hence, local NGOs of young disabled people in Ukraine play the role of intermediates between the disabled youth and the governmental bodies providing an alternative way of development which leads to the better satisfaction of needs of the disabled youth. Moreover, there is substantial need for developing the unified human rights approach to tackling the problems of the disabled youth, of organizing the national network of the NGOs of young disabled people and of establishing the self-advocacy groups which could enforce the legislation work in an appropriate way and ensure human rights satisfaction.

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УКРАЇНЬСКА МОЛОДЬ ІЗ ОСОБЛИВИМИ ПОТРЕБАМИ: УРЯДОВА ПОЛІТИКА ТА ГРОМАДСЬКА ДІЯЛЬНІСТЬ

Анотація

У статті розглянуто деякі важливі питання соціальної політики стосовно молоді з особливими потребами в сучасній Україні. Автор аналізує вітчизняну законодавчу базу, що визначає діяльність уряду та неурядових громадських організацій у сфері соціального захисту та реабілітації молоді з інвалідністю. Подано статистичні дані щодо зростаючої кількості неповносправного населення за період незалежності держави. Охарактеризовано визначальні тенденції громадської діяльності інвалідського руху та виклики, з якими стикаються молоді люди з особливими потребами в Україні.

Ключові слова: молоді з особливими потребами, урядова політика, громадська діяльність, законодавство, соціальний захист, Україна.

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Аннотация

В статье рассмотрены некоторые важные вопросы социальной политики по отношению к молодежи с особыми потребностями в современной Украине. Автор анализирует отечественную законодательную базу, определяющую деятельность правительства и неправительственных общественных организаций в сфере социальной защиты и реабилитации молодежи с инвалидностью. Наведены статистические данные роста инвалидизации населения за время независимости государства. Дана характеристика определяющих тенденций общественной деятельности организаций молодых инвалидов и проблемы, с которыми борются молодые люди с особыми потребностями в Украине.

Ключевые слова: молодежь с особыми потребностями, правительственная политика, общественная деятельность, законодательство, социальная защита, Украина.