

CHILDREN AND DISABILITY IN GEORGIA

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Introduction

In 1994 Georgia joined the Convention on the Rights of the Child, which recognizes that “a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community”.

Certainly one cannot say that either the state on the whole or, in particular, its legislative and executive authorities pay no attention at all to the problem of the disabled children. However, due to the lack of funds, the majority of the planned activities cannot be accomplished. The election programs and action plans of the different political parties actually do not provide for the problems of children and particularly of the disabled children. Although the world practice shows that very often this is the point that attracts the interest of the public and determines their choice.

Unlike the western democratic countries, people in Georgia still demonstrate an inadequate attitude towards the disabled, including the disabled children. One can rarely find a disabled child in schools, offices or other public institutions (this attributes to the grown-up disabled people as well).

Children with disability: who are they?

As mentioned in the document issued by UNICEF (*Children in Georgia: A situation Analysis, Tbilisi, 2000.*), in Georgia, as in other post-totalitarian countries, disabled children are seen as bearing a particular stain. A child with even a slight mental debility could be sent to children’s institution. While institutionalization may not be the best solution, the retarded children are necessarily better off at home where they tend to be psychically isolated from society and their peers. Their life is restricted to the four walls of their room. Few of these children receive the benefit of regular medical treatment. For the most party they have no orthopedic and other support equipment. There is little scope for education and job training. Till 2002 the social protection of the disabled outside institutions from the government was limited to pension payments, 14 lari (less than 2 US\$) per month.

At the present time there are about 9 thousand disabled children (0-15 years of age) registered in Georgia. However, according to the results of Multi Indicator Cluster Studies (MICS), this number is approximately five times as much. While the results of MICS are based on the parents' appraisal, they should be treated with a certain caution. Nevertheless we would suppose that the real number of the disabled children at least 2-3 times exceeds the registered amount. Partially this can be explained by the fact that some parents do not find it necessary to involve the Social Security Authorities in their children's problems. But apparently, the main reason should be the deficiency of the system, which cannot take a proper care of such children and, consequently, is considered to be less attractive.

According to the statistics, by the end of 2001 there were 9197 disabled children in Georgia (about 500 of which were at the same time IDPs). This number makes 5% to the total amount of the disabled people. Although, it would be more precise to attribute this number to the category of children, who just receive disability benefit, while in practice there is a number of the disabled children who are not registered, and at the same time some of the registered children are not actually disabled. Congenital mental and physical disorders are the prevailing reason (about 80% of the other diseases) of the children's disability. The share of the retarded in the total amount of the disabled children is very big. It must be mentioned that from the early 1990s, despite the considerable reduction of the birth rate and of the total amount of population, the number of children referred to this category, has significantly grown (by about 1.5 times). This can be explained mainly by the fact that formerly the families tried to hide the cases of disability, while at the present time they, on the contrary, hope to gain some help by registering their children.

Years	Total number of disabled	Of which children	Disabled children as % to the total number
1989	203276	6073	3.0
1990	205607	6874	3.3
1991	218436	7533	3.4
1992	219297	7385	3.4
1993	226560	8134	3.6
1994	227737	8219	3.6
1995	213756	8502	4.0
1996	194145	7382	3.8
1997	190154	7665	4.0

Years	Total number of disabled	Of which children	Disabled children as % to the total number
1998	190060	8254	4.3
1999	199200	8264	4.1
2000	181409	8534	4.7
2001	185461	9197	5.0

Source: 1989-1998 and 2000-2001 – Social Security Fund, 1999 – State Department on Disability Affairs.

What concerns the statistical information about the disabled children, its main source is the Common State Fund for Social Security. In 1999 the Department on Disability Affairs carried out control over the registration system of the disabled people and ensured the filling of the personal cards for each disabled person. But afterwards the Department, as an independent entity, was closed, the financing was stopped, and hence, the work could not be continued.

In 1995 the law “On Social Protection of the Disabled People” was adopted in Georgia. Several clauses of this law provide for the disabled children. According to this law, the disabled children have additional guarantees to exercise their rights and protect their legal interests. According to this law, the Education authorities together with Social Security powers must ensure the pre-school and out-of-school education for the disabled children.

The law provides the general secondary and special education for the disabled children at general schools, and in case of necessity – at special schools. Studies should be arranged also for those children, who undertake medical treatment at the hospitals or rehabilitation centers. If it is impossible to provide studies in general or special schools, in the pre-school or other kinds of educational institution at the parents’ wish, then the children can be trained at home. In such case the financial security and special discounts for one of the parents or his/her substitute shall be determined by the law.

According to the law, the educational institutions must assist the disabled children’s parents or their substitutes in arranging studies at home. With the purpose of comprehensive and harmonious development of such children, which includes engagement in social activities, art and sports, the educational and other state authorities must arrange the out-of-school studies. In case of long-term (not

permanent) in-patient treatment, the hospital must provide a continuous training for the disabled children, ensuring its correlation with the social and working adaptation.

This law fully reflects the main problem typical to the other social laws recently adopted in Georgia – good will has no financial or institutional support. At the same time there are no Standard Acts that would create a mechanism to enact the law.

It should be mentioned that the current general situation in Georgia cannot guarantee the solution of the disabled people's problems, including those of the disabled children. The current law on social protection of the disabled persons requires considerable changes and amendments.

The Decree #665 of the President of Georgia, dated 14 October 1996, approved the State Program of 1997-2000 for social and medical rehabilitation of the disabled people. In 1997 the Department on Disability Affairs was established. The program was aimed to ensure the equal possibilities for the disabled people, including the children, according to the UN common rules and the Geneva Convention on the Protection of the children. The program provided for elaboration of the projects with the goal to create additional guarantees for the disabled people to exercise their rights and protect their legal interests. The program provided for the equal possibilities for the disabled children, for creating of the additional guarantees of their rights, refurbishment of the boarding houses, supplying with transport, agricultural equipment, cinemachinery, TV and video equipment, domestic equipment, fiction and manuals. It was planned to register the disabled people's condition, to establish and equip the local services, to improve the financial and technical basis of the boarding houses for the disabled, to ensure the step-by-step supply of the prosthetic devices and wheelchairs, to equip the special medical establishments with the up-to-date techniques, to create a system of professional training and retraining of the disabled.

The considerable part of these plans was not put into practice. There are still serious obstacles in the country that prevent the disabled people, including the children, to protect their legal interests.

In March 2002, according to the Presidential Decree “On promoting the activities of the disabled people's non-governmental organizations and on the national coordinating council”, a special Council for disability affairs was established. The Council is chaired by the State Minister (the second person in the executive power)

and is comprised of the representatives of both governmental and non-governmental organizations. However the Council has no actual power and thus it is not clear, in what way it will be possible to follow its decisions.

According to the Legislation, those families, who have a disabled child under 16, receive pensions (allowances) in the amount of 14 Lari. These pensions are often paid irregularly. The Presidential Decree dated 22 March 2002, provided an additional allowance in the amount of 22 Lari for all the disabled children under 16. Those 36 Lari, currently paid to the disabled children, make approximately one third of the healthy person's living wage, which means that this amount should not be sufficient for a disabled person, who has considerable additional expenses.

Institutional care of children with disabilities

The Georgian reforms, taking place from the 1990s mostly affected the children. The poverty of the whole population made it impossible for many families to create proper conditions for growth and development of their children. It often happens that the only way for the parent to avoid starving is to send the child off to the orphanage.

Parents try to send a disabled child to the institution for the following reasons:

- The attitude of the society – it is shameful to have a disabled child;
- Financial difficulties;
- Parents have no skills in nursing the disabled children;
- There is a very small possibility for a disabled child to integrate in the society.

There are 31 institutional establishments for the disabled children in Georgia. Four of them submit to the Ministry of Labor, Public Health and Social Security, while the rest 27 (20 of which are boarding houses) – to the Ministry of Education. Schools and boarding schools for the children with some chronic diseases, physical defects and “moderate” mental deficiency, also submit to the Ministry of Education. Such proportion is logical and aims to place those children, who can learn, in the institutional establishments of the Ministry of Education.

Children from different regions of Georgia study in the 20 boarding schools, submitted to the Ministry of Education. These are schools for the physically and

mentally retarded children. Totally 2.5 thousand children at the age from 7 to 18, study there (47% of them - girls and 53% - boys).

In the Soviet period these boarding schools followed the special educational plans. Properly equipped workshops were available, according to the corresponding area of craft. The children were being prepared for work. That's why the plan always provided more time for the job training. The state was also liable to ensure the children's employment. One can find such approach even positive in comparison with the current difficult situation.

In the system of the Ministry of Labor, Public Health and Social Security there are two boarding schools, two of them – day boarding schools, where the children spend the whole day and one – a hospital. In 2001 the contingent of these establishments was comprised of 240 children, mainly with oligophrenia, debility or imbecility, or also with cerebral palsy. The establishments have training groups, and working therapy groups. Apart of that, there is a disabled children's department in the Tbilisi orphanage for the children under 4.

It must be mentioned that a certain amount of the disabled children (several dozens) are placed in other children's institutions, i.e. in the orphanages for the healthy children.

The breakdown of the contingent of the disabled children's institutions is following: 52% - orphans, 36% - children from the poorest families, 29% - sent by the orphanages, 19% - children who periodically visit their families.

Schools and boarding schools for the disabled children provide poor assistance in establishing of social relations. In fact, the children are isolated from the environment, which makes it difficult to prepare them for the independent life in future.

According to the current legislation, there are relatively high standards for the state financing of the disabled children's institutions. In reality, at the present time the children in such institutions lack elementary living conditions, despite the fact that the situation has considerably improved in comparison with the previous years. The food is insufficient and meager, there are not enough clothes. Most of the orphanages have no heating or hot-water-supply systems. There is always a deficiency of equipment and hygienic devices. Most of the buildings need refurbishment.

The lack of funds is a crucial problem of the special institutions for the disabled children. According to the data of the Ministry of Economy, Industry and Trade, in 1995-1998 the boarding schools were financed mainly by the local budgets. During this period the average expense per one child was from 0.25 to 0.8 Lari (2.5 Lari provided by the corresponding standard). The deficit was filled through the humanitarian aid. From 1999 the children's institutions started to receive finance from the central budget, which was an attempt to improve the children's conditions. However, due to the permanent deficiency of the budget, the government is not able to grant enough money for the children. As an example, in 1998 the state budget provided 1873.8 Lari for the boarding schools (70% of the planned amount), and in 1999 – 3113 Lari (58% of the planned amount).

With the purpose to ensure the optimal financing, from July 2000 the boarding schools for the disabled children are financed in accordance with the accomplished work. In order to enable its operation, each boarding school is granted about 5.3 Lari per day. In the second half of 2000 the state fully reimbursed the boarding schools for the accomplished work in the amount of 97.8 thousand Lari. It is remarkable that from 2002 the daily financing per child has increased from 5.3 Lari to 6 Lari.

Despite certain improvements in the financing of the disabled children's institutional establishments, provided by the Ministry of Labor, Public Health and Social Security, it still does not ensure the financing of rehabilitation process (particularly social rehabilitation), which prevents integration of the disabled children.

According to the Ministry of Labor, Public Health and Social Security, despite the certain improvement in the state financing of the institutional establishments, this program is still deficient. It cannot ensure the financing of rehabilitation process (particularly social rehabilitation). This prevents the efforts to ensure the process of the disabled children's integration in the society. At the same time the material and technical base of the institutional establishments does not meet the today's requirements, the current staff needs a serious retraining.

Most of the buildings, hosting the establishments for children, need refurbishment. They lack even the elementary equipment. Average salary of the staff does not exceed 40 Lari.

In the Soviet period the government provided more care to the disabled children's institutions. In 1989 383 disabled children were placed in 2 boarding schools submitted to the Ministry of Health. These schools were designed to host 600 children. In the first half of the 1990s their number became three times less. So by the end of 1995 only 123 children remained in boarding schools. The number of the staff reduced correspondingly (from 376 to 179). Such decrease of the number of children in boarding schools was mainly caused by the abrupt worsening of the living conditions: poor supply with electricity and fuel, default of the heating systems, insufficient supply with food, clothes and linen. In such situation the humanitarian aid granted by the foreign countries, remained the only source of help to the boarding schools, as well as for other establishments for children.

Children with disabilities in families

At the present time approximately one third (30%) of the disabled children are institutionalized, the rest are brought up in their own families. The disabled children, who live in families, often need a personal nurse. Apart of rare exceptions, the families cannot afford a nurse. So, one of the parents undertakes the nurse's functions. Consequently, he/she cannot work. The family loses an additional source of income. The vast majority of such families belong to the poorest part of the society.

A small part of the children, who live in families, are in better conditions, whilst their families can afford an adequate medical treatment for their children. Medical treatment and special support equipment are unavailable for the majority of the disabled children.

The disabled children and their families live in rather hard financial situation. The total unemployment, low salaries and high prices for medicines make the access to the medical treatment and rehabilitation impossible for such children. The studying of 1000 families with disabled children, carried out in 2001, showed that almost half of these families (475) live in extreme poverty. Due to the lack of funds, most of these children could not afford a visit to the doctor during the past three years. They cannot go out or receive proper education. Their families are unaware of the existing discounts and priorities.

The government pays no attention to the informal education of the disabled children, to their aesthetic education and sports. Only a few non-governmental

organizations work on these issues. With the support of international organizations, they have accomplished a number of cultural and educational projects. However, the programs, conducted at the initiative of only some single non-governmental organizations shall not be able to solve the general problem, until the state strategy is developed.

As already mentioned above, the opinion, that a disabled and especially mentally retarded child is a shame to the family, is still prevailing in Georgia. This is the reason why some children with even only a minor psychical defect are sent off to the special establishments, regardless a quite sufficient financial status of the family. It also often happens that such children are deliberately isolated from the society by their parents. There were cases when practically healthy children were placed in the disabled children's establishments, because of some minor physical defects (for example, harelip or defect of the lobe of ear). As a result of the inappropriate environment these children usually start falling behind.

Education

The Georgian Constitution and the law "On Education" make the legal basis for the disabled children's education in Georgia. This law provides special educational institutions for the children with physical or mental defects, who are inclined to normal development. These institutions provide medical treatment, training, education, social adaptation and integration into the public life. The shortcoming of the law is that it recognizes special training as the only way of giving education to such children.

Together with other difficulties, one of the main problems is that the Georgian society is not yet ready for the inclusion of the disabled children into the regular educational system. Neither the schools or teachers, nor the disabled or healthy children's parents, and nor even the healthy children themselves are ready to admit the disabled children's active participation in the school life, which would contribute to their integration in the society.

According to the law "On Education", the children with physical disabilities, who live in families, receive a guaranteed home education with the help of the teachers' home visits. Under this law, such children shall be registered at schools according to their places of residence, and the teachers shall be assigned to teach them at home. Due to the lack of funds, schools cannot secure such services. So, in reality

such practice could not be established. The Ministry of Education has registered only two cases of the disabled children's home education.

It is factually impossible to provide education to the disabled children in general schools. The reason is the absence of the conditions necessary for the disabled children. However, recently certain improvements were achieved. In particular, several schools in Tbilisi created special conditions on site for those children, who cannot walk. But finally this program could not work, because it appeared impossible to arrange for the special facilities to ensure the children's transportation to school.

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In 2000 the UN Committee on the Rights of the Child, having reviewed the report from Georgia, expressed its concern regarding the lack of efforts in Georgia aimed to integration of the disabled children in general schools and in the whole society. The Committee urged to increase the efforts for deinstitutionalization of such children, to create special educational programs and, where possible, to promote their participation in the school and public life.

Disabled children have many common problems where the financial situation of the family is not the key point. The disabled children, in fact, do not mix with their peers. They are to a great extent dependant upon their families. They have no habits of social life, they show inadequate reactions, they are afraid of activities. 90-95% of the retarded children of the pre-school age are brought up at home, where there are not often proper conditions for their upbringing. Parents have not got the necessary skills that would assist in the development of their children. All the above prevents full socialization of the child, which is the essential condition for his/her independent activities within the society.

From March 2002 the non-governmental organization "Child and Environment", with the support of UNICEF, has launched a project in one of the Tbilisi nursery-kindergartens. The goal of the project is psychological and social rehabilitation of

the disabled children under 3. One of the main objectives is also to provide training for the parents in order to help them in obtaining skills necessary for proper nursing of the disabled children.

The Ministry of Labor, Public Health and Social Security has prepared the deinstitutionalization program for the disabled children. The program is designed to elaborate the mechanisms promoting active operations of the children's institutions, based on the international standards. The program provides for the establishment of multi area rehabilitation centers, more efficient utilization of human resources, improvement of the current legislative basis, etc. Apart of that, the program plans the creation of the system for the disabled children's home care. For this purpose the inter-sector working group shall be established. The ultimate goal of the program is to improve the facilities of psychological, educational and social rehabilitation of the disabled children, and to create an appropriate public viewpoint.

During the year of 2002, the Department on the Disabled Persons at the Ministry of Labor, Public Health and Social Security, together with the non-governmental organization "First Step" is carrying out the deinstitutionalization project for the disabled children, who lack the parental care. The goal of the project is to promote the deinstitutionalization of such children by means of improving the social protection mechanisms and paving the way for the return of such children to their natural (biological) families. In the limits of the project special studies were carried out, which covered the children, who live in the institutions, and their families. The database was prepared. The reasons of sending the children to institutions were systematized. As a result of these studies, a 22 family focus group was created. The families within this group shall possibly be ready to receive their children back after a certain preliminary work. The focus group includes a ten family pilot group, ready for the deinstitutionalization, and also three more families, who have already received their children back, but may send them off to the institutions again. The project is supported by the activities aimed to prepare the public viewpoint. Three films and one poster were designed for social advertisement. The legal services prepared a package of proposals and recommendations for the changes in the current legislation.

In April 2002 the non-governmental organization "First step" established a children's village. The village shall ensure the children, who lack the parental care, with the knowledge, habits and experience necessary for the independent life and shall support their optimal integration in the social environment.

At the present time the first cottage is operating in the village, which hosts 12 disabled children under 15 from the Kaspi psychoneurological boarding house. These children have physical, mental or sensory disabilities. Before the return to their biological families or fosterage, the children will permanently live in the village.

The main principles of the village are as follows:

- Transition from the institutional to the family type of dwelling;
- Interdisciplinary approach to the process of education and rehabilitation.

The children live with so called “Mother” and “Aunts”. Mother is a head of the family. Interdisciplinary group (pediatrician, teacher, occupational therapist, psychologist and social worker) leads the educational and rehabilitation process in close cooperation with the “Mother” and “Aunts”.

The educational process is carried out in the village and in special schools. 8 children of the 12 attend the center of free pedagogics, 2 of them go the school for the deaf and mute, 1 – to the Sunday school, and 1 – to the boarding school. Apart of that, 8 children go in for swimming. All the children have weekly drawing lessons. The children are supported in the development of their functional abilities. They go on excursions, to the cinema, concerts, circus and the Zoo or to the other public places.

All the above contributes not only to the general development of the children, but also to their integration in the social environment.

The village is financed by the Ministry of Labor, Public Health and Social Security, by the “World Vision International” and by the “First Step”.

Accessibility

The common rules of accessibility, generally accepted in the world, do not in fact exist in Georgia. These rules include accessibility in public places, in and outside the building, in transport. Despite the fact that the law “On social protection of the disabled persons” provides for the special requirements to the construction of the public buildings, and even a special authority is determined to supervise the

construction process, still the situation in the country as regards accessibility is very complicated. Such problems, as hard financial conditions, geographical landscape, hereditary are aggravated by the political problems. In particular, the law does not provide for the authority that would be responsible for the protection of the disabled children's rights. The rules of accessibility are not defined according to their priorities. Acceptance of such rules would make it possible to fight for their observance. Mass media facilities do not meet the needs of the disabled. No books in Braille are published. Informational and other telecasts are not translated into dactylic (currently there is only one TV channel that broadcasts one daily 15 minutes informational program). There are no special transport facilities for the disabled people, and so on.

Only in some central districts of the capital city of Tbilisi the non-governmental organization "League of the Disabled Persons" has arranged special slopes from the pavements to the roadway. The League has also imported special buses from the USA, the back doors of which were designed for the disabled people. During a number of years these buses moved along the city routes, but however the back doors never functioned. Certainly the efforts of this single organization are not enough to solve the general problem.

Conclusion

Currently the Georgian government, in close cooperation with UNICEF, is preparing a Common National Action Program for the period till 2007. The program provides the support to the set of children's civil, economic, social and cultural rights, acknowledged by the Convention on the Rights of the Child, in the context of ensuring the children's dignity. The program provides for the child as an active subject, i.e. a citizen, who has rights in every area of life. Three aspects of the rights were distinguished: security, protection and participation.

The program pays particular attention to the improvement of those children's conditions, who are disabled or live in special conditions. In this direction the program provides the following:

- Prevention of the children's disability;
- Ensuring of equal possibilities for the disabled children, according to the UN standard rules and the Geneva Convention on the Protection of Children, and

also developing of the projects, which provide the additional guarantees to the protection of the disabled children's rights and legal interests;

- Increasing the efficiency of the disabled children's rehabilitation;
- Complex solution of the problems related to the disabled children and their parents;
- Strengthening of the disabled children's self-confidence, contributing to the development of their abilities, according to the area of their interest;
- Preparation of the disabled children to the future independent life.

The program requires deep economical, financial and legal studies. It shall be accomplished on the basis of the corresponding legal enactments and annual plans developed by the executive authorities.