

CHILDREN AND DISABILITY IN UKRAINE

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REPUBLIC OF UKRAINE

1. The Government's obligations towards children with disabilities

At present, the problem of support for the disabled is acquiring special importance for Ukraine, as a result of continuing growth in their proportion among the general population structure. In the last ten years, the number of disabled persons in Ukraine has increased from 2.0335 million to 2.6591 million (from 3.9% to 5.5%).

In order to safeguard the rights of the disabled, a number of legislative acts have been drafted and adopted, in which all the political, socio-economic, and individual rights and liberties of the disabled are fixed. Under Ukraine's law "On the Fundamentals of the Social Protection of the Disabled in Ukraine", a person with persistent functional derangements resulting from illness, the aftermath of a trauma, or congenital defects, and which lead to the restriction of vital activity, and to the need for social assistance and protection, is classified as disabled.

Disabled children with defects in their physical and mental development demand particular government's care and attention. Considering the limitations in their opportunities for social contact, their abilities to look after themselves, and their freedom of movement, the development of these children depends to a large extent on meeting their needs. Therefore, the problems of childhood disability in the social protection system remain highly relevant. As of January 1, 2002, 153,000 disabled children under 16 were registered with social protection agencies in Ukraine, and were receiving disability pensions; this amounts to 169 disabled children per every 10,000 children of corresponding age.

Today, the government policy with respect to social protection of the disabled is based on the provisions of the Ukrainian Constitution, and the laws "On the Fundamentals of Social Protection of the Disabled in Ukraine", "On the Status of War Veterans, and Guarantees of Their Social Protection", "On the Status and Social Protection of Citizens Affected by the Chernobyl Disaster", "On the Provision of Pensions", "On the Employment of the Population", and "On Education".

An analysis of the provisions in Ukrainian law concerning the protection of children's rights enables to make an expert conclusion on whether these legally formalized provisions conform to, or whether they are as close as possible to international norms and standards, which have been fixed in the UN Convention on the Rights of the Child, the World Declaration on the Survival, Protection, and Development of Children, and the Plan of Action for its implementation. A similar conclusion can also be drawn concerning the obligations of the Ukrainian Government towards disabled children. Ukraine's accession to different international agreements has made certain important international legal documents on social protection for the disabled binding on the country's government. These include, in particular: the Standard Rules on the Equalization of Opportunities for Persons with Disabilities approved by UN General Assembly Resolution No. 48/96 of December 20, 1993, and for which Ukraine also voted; the European Social Charter, which Ukraine signed on May 2, 1996, as a member of the Council of Europe. Today, however, there is no precise mechanism in Ukraine either for implementing the provisions of the European Social Charter or for monitoring the conformity of national regulations to the Charter's provisions.

In Ukraine, the law "On the Fundamentals of Social Protection of Disabled in Ukraine" entered into force on March 21, 1991. Its provisions were focused on providing social protection for persons with disabilities, including disabled children.

In analyzing the primary measures for providing social protection for the disabled, it is impossible to ignore the issues of social safeguards for citizens affected by the Chernobyl disaster. Since a worsening

has been observed in recent years in the health of the affected population, the social protection system ought to create the conditions necessary to improve their health and raise their living standards.

The government's responsibilities with regard to disabled children include creating the legal, economic, political, living, and socio-psychological conditions necessary to restore their health, support them materially, and to engage them in labour and social activities within their capacity. Social protection of the disabled by the government involves extending financial assistance; supplying the means for moving around and prostheses; audio and visual aids; helping install special equipment in the homes of the disabled; providing them with guardians and care givers; and adapting buildings, public transport, and means of communication to the special needs of the disabled.

The above obligations are being fulfilled in the following way: the pre-school upbringing and education of disabled children is carried out in both general and special pre-school educational institutions, while the gifted disabled children have the right to cost-free instruction in music and the fine and applied arts in general or special extra-curricular educational institutions. Families with disabled children have a preferential right to the upgrading of their living conditions, in a manner stipulated by effective Ukrainian legislation. Disabled children who either do not have parents or whose parents have been deprived of their parental rights, and who live in public or other children's institutions, have the right, upon reaching the age of majority, to the priority receipt of housing and material assistance for its improvement, so long as they are capable, in the opinion of professional medical and social workers, of living by themselves.

A great deal of attention is given in the country to the education of disabled children. Thus, a statute of a special general educational residential school (*internat*) for children with physical or mental disabilities was approved by order of the Ukrainian Ministry of Education on May 13, 1993. The chief aim of a residential school is to develop and form their personality; assist them in social and psychological rehabilitation, and prepare them to eventually do some kind of job; and educate them in their rights and duties as citizens.

The statute also defines the different types of educational and child-rearing institutions with pre-school departments attached to them, for children who: are deaf or have dull hearing; are blind or have depraved vision; have serious speech defects; suffer from the effects of poliomyelitis or cerebral paralysis; and/or are mentally retarded.

The special schools operate at three levels:

Level 1: Primary school, which provides an elementary general education;

Level 2: Basic school, which provides an incomplete general education;

Level 3: Higher school, which provides a complete general education.

The special schools of all three levels can, depending on local conditions, function autonomously (as separate primary, basic, and higher schools); or as an integrated institution or in combination with pre-school establishments (as departments).

In addition, the decree "On Measures to Improve Work on the Rehabilitation of Children with Organic Damage to the Nervous System" was issued by the Ukrainian Cabinet of Ministers on February 29, 1996. As a result, the Ukrainian Centre for the Rehabilitation of Children with Disabilities was set up to improve the rehabilitation of children with organic damage to their nervous systems (including infantile cerebral paralysis); regulations regarding the operation of the Centre were approved; and it was determined that the financing of the Centre would be done by general allocations from the Ukrainian state budget.

In order to strengthen the social safeguards of the category of the disabled most in need of protection (namely, disabled children and those disabled since childhood), the national Law "On Government Social Assistance to Those Disabled Since Childhood and Disabled Children" was passed by the Ukrainian Supreme Council on November 16, 2000.

At the heart of this law lies the principle of material support for disabled children and those disabled since childhood, in the amounts not lower than the subsistence level (which is set, in accordance with Ukraine's effective social standard, at an average of \$23 per month) for persons who have lost capability. The amount of the assistance provided for by this law is established as a percentage of the above minimum subsistence level, determined in accordance with the age of the disabled child, and the ability of the person disabled since childhood to guarantee, through his/her own labour, a dignified and worthwhile existence in society (on the basis of the disability categories, from Group I to Group III, established by a medical commission).

Taking into account the total lack of ability to work among those disabled since childhood in Group I, and the need for the additional costs involved in caring for them, this law formalized the allocation of an additional allowance amounting to 50% of the minimum subsistence level, for the care of those who have lost all ability to work.

The law also provides for the allowance for the care of disabled children up to the age of 16, who because of their minor status and state of health require additional expenditures on the part of their parents, so that they do not have to enter adult life as full dependants of the state, and can acquire the skills needed for an independent existence, and engage in work that is beneficial to society. In order to provide material support to families who lack adequate financial means, supplemental funds, in the form of allowance for the care of disabled children, are provided for by the law. Single mothers (and single fathers) of disabled children also have the right to receive allowance for their care, regardless of whether the single parent works, and the size of the family's aggregate income. The allowance for the care of a disabled child is granted, in addition, to one of the non-working (but able-bodied) parents, foster/adoptive parents, or guardians who actually takes care of the disabled child.

In 2002, 285.6 million *hryvnas* was earmarked for the first time in the Ukraine State Budget for providing government social assistance to disabled children, and those disabled since childhood.

The amount of the above assistance to those disabled since childhood in Group I, with the account of the allowance for their care, is 120 *hryvnas* per child. The amount of government social assistance to disabled children and those disabled since childhood in Group II is 56 *hryvnas*; while that to disabled children and those disabled since childhood in Group III is 40 *hryvnas*. For those eligible for the allowance, government social assistance to a disabled child is set at 80 *hryvnas* if he or she is under 6, and at 96 *hryvnas* if he or she is from 6 to 16 years of age.

The above sums are actually quite small primarily due to the economic problems in Ukraine. If compared to the minimum subsistence level, social pensions for the overwhelming majority of the disabled within these categories exceed the amount of social assistance. That is why today, government social payments are received by only 10,000 persons, or 3% of the total number of disabled children and those disabled since childhood.

These figures demonstrate that under such conditions, the Ukrainian law "On Government Social Assistance to Those Disabled Since Childhood and Disabled Children" does not guarantee any improvement in their material status, and does not facilitate their adaptation to society.

It is clear, however, from the nationwide program The Children of Ukraine, that the country's government authorities recognize that the problem of social protection of disabled children and

children with developmental defects does exist, and are going to draft new regulatory acts, aimed at promoting those children's development and quality of life.

Such social support for citizens with limited physical opportunities is one of the most important lines of the Strategy for the Prevention of Poverty, approved by Presidential Decree No. 637\2001, dated August 15, 2001. One of the main conditions for preventing poverty ought to be a government policy for supporting the disabled, focused on their maximum adaptation to life in society, their occupational rehabilitation, the creation of conditions for their employment, and prevention of their social isolation.

The issues of improving the social protection system for the disabled are highlighted in the Guidelines for Social Policy for the Period up to 2004, approved by Presidential Decree No. 717\2000, dated May 24, 2000.

Work on improving the legislation in the area of social protection of the disabled, both adults and children, continues.

2. The dynamics of childhood disability

The problems of childhood disability in the system of preventive healthcare measures remains of extreme relevance. This is caused by deterioration in the state of health of both women of reproductive age, and of the child population; the increasingly high rate at which certain diseases are becoming chronic; and other factors. The influence of the genetic factor is also highly important. Mortality due to these causes has increased over the last decade from 3% to 4%, while the genetic factor is responsible for 7 out of every 1,000 infants becoming disabled.

As of January 1, 2002, 153,000 disabled children below the age of 16 were registered in Ukraine; that is, 169 out of every 10,000 children in this age group. Thus, compared to 1992, the level of disability in general among children grew by more than 69%, while that of disability resulting from congenital developmental defects increased almost fourfold.

The majority of disabled children live in towns and cities. The greater share of disabled children (89%) are being raised at home.

In the age structure of child disability, the largest proportion (79%) belongs to the category of children aged 7-15. The disabled belonging to this age group dominate in practically every class of diseases making up the causative disability structure. Thus, these youngsters account for 78% of all disabled children with neoplasms, 84% of those with endocrine pathologies, 89% of those with mental disorders, and 73% of those with diseases of the nervous system.

Diseases of the nervous system hold first place (24%) in the causative structure of child disability; congenital anomalies are in second place (19.7%), while mental and behavioural disorders come third (16%).

The causative structure of the primary disability is a bit different. Here, the largest proportion (20%) belongs to congenital anomalies, diseases of the nervous system are in second place (18.6%) and mental and behavioural disorders come third (16%).

In just the last few years, a number of regulatory acts, designed to prevent child disability, strengthen the preventive focus in the healthcare system, and improve the quality of children's medical services, have been approved. The following are the Presidential Decrees issued with the aim of preventing child disability:

- "On a Targeted Comprehensive Programme of Genetic Monitoring in Ukraine for the Years 1999-2003";
- "On Approving the Concept of Developing Public Health Care in Ukraine";
- "On Additional Measures for Ensuring the Implementation of the National Programme – The Children of Ukraine – in the Period Leading Up to 2005";
- "On the Reproductive Health 2001-2005 National Programme".

Thus, the main tasks of the obstetric-gynecological and pediatric services in the prevention of child disability are: early identification of the risk of giving birth to a disabled child; early diagnosis of the diseases that threaten child disability; early preventive therapy, habilitation, and rehabilitation which will either help to prevent child disability or significantly increase the level of the disabled child's functional and social adaptation.

Among the measures facilitating the solution of child disability problems, the following should be noted:

- Improving perinatal services and widely introducing advanced perinatal technologies;
- Preventing disability through improving the organization of quality medical assistance for pregnant women, women in childbirth, and newborns;
- Improving the quality of preventive work with almost-healthy children, raising the quality of medical services, and expanding the specialized assistance to children (on the basis of adopted standards);
- Improving the system of logistical support to medical and preventive institutions;
- Developing a network of rehabilitation institutions for comprehensive treatment aimed at restoring the health of children with physical and mental disorders;
- Developing a network of sanatoria for the treatment of disabled children who require constant care;
- Expanding the network of genetic research and treatment establishments (today, seven inter-regional and sixty-four consultative centres exist);
- Creating a network of medical/social institutions for the short-term accommodation of disabled children (for a week or a month), depending on the needs of the family and the child-rearing plan.

Chronic somatic illnesses account for around 32%-35% of the cases in the structure of child disability; however, in the disability structure of young people of working age (up to 39), they account for more than half (56%) of all cases, and it is due to somatic pathologies that the general disability index for this age group is growing.

These data once again confirm the fact that the majority of chronic somatic illnesses start in childhood and adolescence, and demand effective rehabilitation programmes.

Cardiovascular and rheumatic conditions, which in Ukraine are the main cause of mortality and disability among young people of working age, hold a special place among chronic somatic pathologies. In addition, around 3,000 children are born each year with congenital heart and great vessels disorders, all of whom require immediate therapeutic intervention and professional observation.

The problem of developing rehabilitation programmes for disabled children with chronic somatic illnesses, and children with mental and physical development limitations, is now one of great relevance, which is corroborated by research into the causes of, and factors that facilitate the occurrence and shaping of disability induced by the above diseases.

At the Ukraine Academy of Medical Sciences' Institute of Child and Adolescent Health Care, a research programme titled "The Principles of Rehabilitating Disabled Children with Somatic Pathologies and Children with Limited Physical and Mental Capabilities" was conducted from 1997 through the year 2000.

The results of this research show that in the last ten years, the number of disabled persons (mostly children and adolescents) with mental disorders has increased by a factor of almost 3.5. Oligophrenia (68%), schizophrenia (11.9%), and epilepsy (9.4%) dominate the structure of mental disorders in disabled children above the age of 14. Organic diseases of the central nervous system account for 10.7% of all cases.

In connection with this, early disability (occurring before the age of majority and prior to working age) requires that specific measures be taken to prevent the further progression of mental disorders and social desadaptation, since the survey of these children's mental status shows that only 75% of those attending school have their level of intellectual achievement corresponding to their age norms.

Still, a great many rehabilitation measures have proven to be largely ineffective. The psychological condition of the disabled child is essential for the effective implementation of rehabilitation programmes: Where and in what kind of family is he or she being raised?

Studies have shown that the majority (80%) of disabled children lack for a healthy psychological climate in the family. The following factors had a destabilizing influence on the atmosphere in the family: an inadequate attitude to the disabled child within his or her family, a low level of internal cohesion and cooperation, a lack of mutual understanding and patience, a lowering in the parents' social role adequacy, and a generally low level in the parents' education and living standards.

It must be especially emphasized that providing social protection of the disabled children who, due to the specific features of their diseases, deviations in mental development, and limited ability to look after themselves, are raised and educated at home, is an important and laborious task. The parents of these children (who are, as a rule, either young couples or single mothers) encounter not just medical and economic problems, but social problems as well. The psychological stereotypes with regard to the disabled remain little changed among the public. Disdain, lack of respect, and fear are some of the reasons for the obstacles to developing the abilities of the disabled, this leading to their isolation. Therefore, the problem of integrating people with special needs is closely connected with the task of helping all healthy people find a way of communicating with their fellow citizens whom nature has deprived of hearing or vision, or the abilities for freely getting around and fully perceiving the world – and do it not through individual acts of kindness, but through creating a comprehensive system of social adaptation for this category of the population.

All of the above testifies to the need for introducing a comprehensive approach to the content and form of the rehabilitation programmes for disabled children.

In order to solve the problem of the rehabilitation of disabled children, it is necessary to create a uniform national system of rehabilitation, one which could unite the efforts of both the rehabilitation services and those undergoing rehabilitation, along with the members of their families.

An important component of this programme would be the occupational guidance of disabled children, and their eventual employment. A draft List of Occupations has been developed to date for different categories of disabled children (children with sensory or endocrine pathologies; cardiovascular and rheumatic illnesses; and mental development disorders – oligophrenia reaching the stage of debility). For the purpose 1,070 children with sensory pathologies, 290 with oligophrenia, 100 with *diabetes mellitus*, and 54 with cardiovascular and rheumatic conditions have been examined.

Important prerequisites for drawing up the list of occupations for disabled children and adolescents were the intensive study of the structure of the illnesses that lead to disability; establishing the accompanying pathologies and complications; determining to what degree the body's disrupted functions are compensated for, and how the psychological characteristics of disabled children correspond to the needs of the occupations they are trained for; and determining their work and occupational limitations.

Among the illnesses largely inducing the development of the major disorders that lead to disability are diseases of the organs of vision and hearing; those of the cardiovascular and endocrine systems; and those which limit mental development. It was for these groups of illnesses that the List of Occupations was developed.

An analysis done of the pathologies which cause disability, and of the psychological characteristics studied, allows one to compare them with the demands which the occupations would make of disabled children, to evaluate the indicators of work limitations, and to identify the possibilities for the occupational rehabilitation of children and adolescents.

For example, the draft List of Occupations, which is recommended for the training and employment of those disabled since childhood with pathologies of the organs of vision and hearing, includes 37 occupations and areas of specialization for blue- and white-collar workers. The draft List of Occupations for disabled children with oligophrenia at the stage of debility includes 17 blue-collar occupations, primarily in agriculture, construction, and industry. Twenty "professionographic" charts for training blue-collar workers in 9 professions, and white-collar workers in 11 professions, are included in the List of Occupations for disabled children with cardiovascular pathologies. For children with disorders of the endocrine system, a List of Occupations has also been drawn up that includes 3 blue-collar professions, and 7 white-collar professions.

3. The causes and ways of institutionalizing children with functional limitations

Preventing the institutionalization of children with functional limitations is an important factor in their future existence. In this respect, the following positive trends now transpiring in Ukraine must be noted: **Over the last ten years, the proportion of disabled children being raised at home has increased from 70.6% to 89.5% of the overall number of children classified as disabled. However, there still is concern over the fact that 1,000 children with disabilities are growing up in the Ministry of Health infant homes, 9,700 are growing up in specialized children's homes or other residential schools run by the Ministry of Education, and 4,700 are growing up in residential children's homes run by the Ministry of Labour and Social Policy.**

The separation of children with functional limitations from their families is caused by:

- Flaws in the system of government assistance for such children;
- Insufficient coordination of the different spheres of activity – medical, pedagogical, and social – that come under the purview of different government agencies, and therefore a failure to observe the principle of offering assistance in a multidisciplinary fashion.

Children with functional limitations end up in the institutional system the same way as healthy children do:

- The children are abandoned by their parents at birth, or a decision is made to leave the newborn child at the maternity home due to its having congenital abnormalities or diseases;
- The children are placed at an institutional establishment by their parents.

The main reasons for institutionalizing a child at different ages:

- A lack of information on the prospects for the child's development, and on the societal mechanisms for helping families who bring up children with functional limitations (the initial information usually comes from medical workers who do not always have expert knowledge of the latest possibilities for social rehabilitation, the legal aspect of the problem, or the experience of public organizations);
- The inability of parents to take the requisite rehabilitation measures, employ special defectological methods for educating children, facilitate social adaptation of children, and effectively inculcate necessary everyday habits;
- The impossibility of guaranteeing the constant care a child requires (a lack of non-working family members, no access to day-care facilities, or sources of economic support);
- A lack of money (the aggregate amount of a child pension and child-care allowance totals only one-third of the survival minimum per one person);
- A disinclination by the parents (especially incomplete families, which make up a large share of the families raising children with disabilities) to remain bound for the rest of their lives to a child at home, and be deprived of a personal life and the chance to make use of their professional skills.

Ways of institutionalization:

- The parents voluntarily abandon their children at birth due to their having congenital defects and diseases primarily because they draw information from medical sources. The prospects for the child's development are often explained to the parents without the participation of a social worker, and it is mainly the medical aspect of the problem which is discussed. If the parents themselves are not capable of seeking out more detailed information, the decision to place the child at the institutional establishment is prompted by a lack of objective information on the family's future prospects.
- The handing over of children by their parents to the social protection system's institutions at an older age (under 16) occurs on the basis of examination by the expert medical/social commissions that exist within the regional healthcare departments. The entire procedure is of a primarily medical nature.

A commission examination referral is issued by the medical consultative commission of the healthcare facility at the child's place of residence, on basis of a "Medical and Social Report on a Disabled Child", compiled by medical personnel without the participation of social workers. Only medical aspects are taken into account; the pedagogues' and the social workers' do not contribute to the diagnosis at this stage.

The role of the parents (and even more so, that of the child itself) is insignificant in drafting the Report. The medical commission does not deal with the family on a dialogue basis, when proposing comprehensive measures to prevent the child's institutionalization.

Thus, an evaluation of the existing procedures and mechanisms for documenting the disability of a child from the perspective of avoiding his or her institutionalization demonstrates that the system now in place favours formalizing institutional care, rather than preventing it. The practice of institutionalizing disabled children reveals the inadequacy of the current, primarily medical, model of diagnosing disability, in which the role of the social worker is clearly insufficient in all procedures, and at all stages where measures might be taken to prevent institutionalization. The lack of knowledge and ideas on options of and mechanisms for

reforming the current (medical) model of diagnosing disability, and steering it closer to more advanced social models, is now being felt in society.

It should be noted, however, that it is precisely on the basis of the analysis of the grounds on which children with functional limitations are institutionalized that the lines along which the social support system for families raising such children should be improved are now being determined:

- Providing parents with necessary and sufficient information on the prospects for their child's development, and on the social mechanisms for providing assistance;
- Providing families with access to qualified services for medical rehabilitation, special pedagogical (defectological) assistance, and social adaptation;
- Providing families with access to day-care centres that are capable of looking after disabled children, thereby giving parents the opportunity to work;
- Increasing the amount of payments to families raising children with functional limitations.

The analysis of disabled children's life prospects emphasises the importance of their getting support from their families.

The prospects for preparing children with functional limitations for adult life.

Continuing education

Under effective legislation:

Children with limited physical abilities but normal intellect, who have been raised in residential institutions and have finished the 9th grade of basic school or received a secondary education, leave to find employment or to study in other educational institutions.

In practice:

Most of the graduates from residential institutions, or of the children from incomplete and poor families, who do not have a possibility to study in higher or vocational educational institutions on a tuition basis, experience contrived difficulties when entering higher educational institutions, especially government-run ones, where competition for admission is high, and with parallel forms of study (paid and tuition-free); a definite proportion of young people with certain physical disabilities are unable to study in these institutions, because transportation means and facilities are not adjusted to their needs.

Very few of these institutions offer disabled children a real opportunity to continue their education, although innovations have been made in this area in recent years. It is now possible to get an education at the vo-tech, college, lyceum, or technical-college level in one of the Ministry of Labour and Social Policy's appropriate establishments. For this, it is necessary to have a warrant issued by the local department of the social protection administration. **However, there are only six such institutions in different cities across the country. They are far from accessible to everyone; they operate on the residential school principle; and, most important, they are not capable of solving the problem fully.**

Finding a job

<p>Under effective legislation:</p> <ul style="list-style-type: none"> - A quota for the employment of disabled persons has been established (4% of all workers); - The National Employment Service keeps a record of persons with functional limitations (in cases where disability has been certified), and jobs in the workplace which they might be able to fill; helps those who turn to it in finding a job (in accordance with the recommendations of the Expert Medical and Social Commission); is available for consultation on matters of finding a job, training and re-training; and informs local social protection agencies of the employment of disabled persons. 	<p>In practice:</p> <ul style="list-style-type: none"> - Employers do not adhere to the quotas, in spite of the mandatory fines that can be imposed; - In 2001, there were almost 7,000 disabled persons (out of a total of 2.5 million) registered with the National Employment Service; only 3,400 of them were able to find jobs through the Service, and less than half of these were given positions specifically reserved for the persons with disabilities. In fact, 1,700 disabled persons refused to accept these jobs, and went to work on general grounds. - The jobs that are reserved often do not meet minimum workplace safety standards, or the professional level of those with functional disabilities. - Jobs are often reserved in government-owned enterprises; many of these are currently idle, and are in arrears with wages.
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Housing

<p>Under effective legislation:</p> <ul style="list-style-type: none"> - For those being brought up in the institutional system, housing is retained for no longer than twelve months unless anybody from the family is living in his or her apartment; - If, by the time of leaving the residential school the child has become an orphan, and more than a year has passed since his or her apartment was vacated, the government is obligated to provide him or her with other housing. 	<p>In practice:</p> <ul style="list-style-type: none"> - The authority of social workers to uphold the housing rights of children is not sufficiently broad as to demand that the heads of local government administrations provide housing. The children are in no position to resolve this problem on their own. As a rule, the grown-up residential school inmates are then transferred to residential homes for the disabled, becoming permanent wards of the institutional system.
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The personnel at different residential institutions say it is a rare and exceptional case when they are fortunate enough to officially arrange for housing for their charges; or to place them at a dormitory provided by an enterprise where they found a job.

Preventing the institutionalization of disabled children could primarily be done through two institutions, which might act simultaneously, in parallel, or in cooperation with one another:

1. The institution of foster families for disabled children, whether operating on a permanent or temporary basis.

2. The institution of day care centres that are capable of: providing effective services to children with functional limitations, and the members of their families (biological or foster); extending these services to the disabled for as long as they live; and providing them with a complete range of services (medical, educational, social, helping them to realize their creative abilities, widen their circle of acquaintances, get training and job placement, and protect their housing and property rights).

4. Education for the disabled

Pre-school and school education for children with special needs

Under Ukraine's legislation on education and on the foundations of social protection for the disabled, work is being done by the Ukraine Ministry of Education to guarantee the development, schooling and upbringing, medical and social rehabilitation, and adaptation to and participation in the normal life of society for children with developmental deficiencies, according to their individual abilities, interests, and opportunities.

Special pre-school educational institutions, residential schools, educational and schooling complexes, educational-rehabilitation centres, and special classes in ordinary primary and secondary schools, are being organized for disabled children whose state of health prevents them from being brought up and educated on general grounds within the educational system's academic and child-rearing institutions. **In 2001, 15,848 and 60,472 children with problems of physical and/or mental development – the majority of whom were considered disabled – were being brought up and educated in 181 special pre-school establishments and 393 special general-education residential schools (of which there were 8 types), respectively. In addition, more than 7,000 disabled children were attending special classes in ordinary general education schools.** These classes conduct studies according to individual curricula and programmes developed and approved by the Ukraine Ministry of Education.

Special residential schools

(at the beginning of the school year)

Type of residential school	1995/96		2001/02	
	Number of residential schools (units)	Number of students (persons)	Number of residential schools (units)	Number of students (persons)
Total:	387	60,200	393	60,472
Including:				
For the mentally retarded (auxiliary)	246	38,027	236	37,545
Of these:				
Residential schools				
for orphaned children	12	1,732	21	3,660
for the blind	6	734	6	850
for those with weak sight	23	3,990	25	4,362
for the deaf	33	4,480	33	3,824
for those with poor hearing	-	-	-	-
for those who grew deaf later	24	3,559	26	3,393
for children afflicted by poliomyelitis and cerebral paralyses	15	2,091	19	2,282
for children with severe speech defects	14	3,182	14	3,157
for children with retarded mental development	26	4,200	34	5,059

The upbringing, education, and upkeep of pre-school and school-age children with developmental deficiencies in ordinary general educational and special educational institutions *is fully subsidized by the government*. To improve the quality of the food served to children living in children's residential homes, 43 subsidiary farms have been set up, out of whose agricultural production from 50% to 80% of the homes' basic food needs are now met.

Should it become impossible to educate disabled children in the educational system's pre-school establishments, ordinary general education schools, and specialized institutions, the education management agencies, on the initiative of the parents (or persons who substitute them) or students, provide individual schooling for the children, in accordance with the Regulation on Individual Schooling for Students in the General Secondary School System.

Talented disabled children have the right to study music, and the fine and applied arts, *free of charge* in specialized schools or in extramural educational institutions.

Those growing up in children's homes and residential schools are provided with prostheses and orthopaedic appliances, hearing aids, eyeglasses, contact lenses, and other means for the individual correction of developmental deficiencies *at the state budget's expense*.

In order to ensure the children's normal physical and mental development and health care, physicians, junior medical personnel, psychologists, and social workers are taken on the staff of pre-school and residential institutions. Those being raised in residential institutions undergo a complete physical examination twice a year to determine outpatient follow-up they need.

The main burden in implementing the policy of social protection of disabled children rests on the Ministry of Labour and Social Policy's specialized educational institutions. These institutions focus on

updating the content of education and the methodology of the social-rehabilitational and educational processes. New programmes are being drawn up, along with special textbooks for the different types of special residential schools for disabled children. Ways and methods for correcting children's deficiencies are differentiated from those for developing their abilities and talents.

Children with most severe disabilities are concentrated in the Ministry of Labour and Social Policy's system of children's homes and residential schools; of these children, around 25% are transferred to residential homes for adults upon reaching the age of majority; around one-third go back to their parents; 3% enter educational institutions run by the Ministry of Labour and Social Policy; and 1% find employment. Around 30% of them die before reaching the age of majority. Serious problems arise in connection with finding jobs for graduates from specialized residential schools for children with psychophysical disorders; there are around 6,500-7,000 such individuals yearly, of whom more than 4,000 are mentally retarded.

One of the main tasks of any school is preparing its alumni to adapt themselves to contemporary economic conditions, and to their entering the unknown, complex world of production, business, and human relations. However, as practice has shown, the alumni of special residential schools turn out to be non-competitive in the labour market, due to a variety of circumstances. Among these, the most important are:

- Low levels of training;
- The limited choice of occupations offered to residential schools, many of which are often not in demand in the current economic circumstances;
- The lack of opportunities to continue their vocational education, or to learn a second profession within the vocational-technical educational system.

In spite of today's complicated socio-economic conditions, one can now point to positive trends in the development of special education. The network of institutions for children with developmental problems is being improved, with new types of establishments being created (such as educational and schooling complexes and educational-rehabilitation centres), and specialized classes for talented children opening. Experience continues to grow as work proceeds on the integrated education and rearing of children with developmental deficiencies among children of the same age. Thus, in 128 pre-school establishments for children with disorders of the locomotor system (6,100 individuals), there are 101 groups for disabled children with infantile cerebral paralysis (603 individuals). More than 6,000 children with mental developmental disorders attend special classes in ordinary schools. Groups for mentally-retarded alumni of auxiliary schools have been opened in all vocational-technical institutions.

In accordance with Ukraine's Law "On General Secondary Education", one-third of all special residential schools for children with hearing, vision, and locomotor system disorders have been redesigned into Level 1-3 institutions, which will offer their students a secondary education and professional training.

However, solving the problems of disabled children – particularly those who are studying and being raised in special general educational institutions – is complicated as a consequence of insufficient and unstable financing: with each passing year, the educational and material base of special pre-school and residential institutions grows worse; nutritional standards are not met; training, technological, and medical equipment need to be replaced, as well as educational and methodological aids, and equipment for the correction and rehabilitation of disabled children with hearing, sight, and locomotor system disorders are ageing or entirely absent; and computer equipment for increasing the effectiveness of the educational-rehabilitation process and linking disabled children with the surrounding world is completely inadequate.

Control must be strengthened over the implementation of Ukraine's Law "On the Employing of the Population Employment" with regard to providing jobs for the disabled alumni of special general educational institutions, since around 5%-7% of those alumni who do not continue their studies remain unemployed.

Vocational-technical education for the disabled. In 2001, the number of disabled students attending vocational-technical (vo-tech) schools in Ukraine was 3,826, or 50% more than in 1992. In particular, there were 3,300 disabled students attending the vo-tech schools run by the Ministry of Education (or almost 1% of the overall number studying at vo-techs).

Special groups are now being organized (according to the type of affliction) at vo-techs to solve the problems of this category of students' adaptation to and involvement in the normal life of society. There are already more than 100 such groups.

In accordance with the specifics of a vo-tech's contingent of disabled students (around half of whom require increased social protection), some schools have begun issuing their own manufactured and agricultural products and offering services to the public, to the tune of around 30 million *hrivnas* annually. This allows them to solve the following problems:

- Instilling in their students the confidence that they can effectively convert their knowledge into practical activities, thereby forming in them the desire to go out and find a job in their chosen profession, since the problem of finding employment is not, under current circumstances, limited solely to the availability of concrete positions;
- Improving the physical infrastructure of vo-techs, and providing social protection at a higher level for those taking part in the rearing-educational process.

Preparing the disabled for study in higher educational institutions (tertiary education). The goal of pre-tertiary preparatory education is to adapt the graduating student's level of knowledge to the demands of higher educational institutions' entrance exams. Unfortunately, it is precisely at this stage that significant barriers to disabled individuals' further studies arise:

- Pre-tertiary preparatory education is tuition-based, rather than free of charge;
- The lack of programmes and methodology for preparatory education designed for graduating students with limited physical abilities.

One result of this is an increase in the gap between the levels of preparation for entrance exams of the disabled and other entrants.

A number of guarantees and privileges are given to the disabled so that they can get a higher education in government-run tertiary institutions. These include:

1. The enrolment of disabled students from Groups 1 and 2 is done on a non-competitive basis, provided they simply pass their entrance exams;
2. Upon the recommendation of healthcare and social protection agencies, the entrance commissions examine the possibility of a disabled student enrolling in a tertiary institution based on the results of an interview, with those who are physically incapable of attending classes at the institution having the right to study at their place of residence, while also creating the conditions for them to complete a course (*i.e.*, take exams) without attending classes;
3. Enrolling students disabled as a result of the Chernobyl disaster bypassing the regular competitive entrance process.

Positive trends include an increase in the number of disabled students enrolled in Ukraine's higher educational institutions. The number of disabled students attending tertiary institutions at accreditation

levels 1-2 grew in 2001 by a factor of 2.1, compared with 1994, and totalled 3,540 individuals. The number of disabled students attending tertiary institutions at accreditation levels 3-4 grew by a factor of 2.7, compared with 1994, and totalled 2,522 individuals. However, the proportion of disabled individuals among secondary and tertiary students remains very, very small. Among those attending tertiary institutions at accreditation levels 1-2, the disabled accounted for only 0.6% of the student body, and just 0.2% of those attending tertiary institutions at accreditation level 3-4.

Number of disabled students studying at higher educational institutions

(at the beginning of the academic year)

	95/96	96/97	97/98	98/99	99/00	00/01	01/02
Tertiary institutions at accreditation levels 1-2, individuals	1,638	1,731	1,774	1,971	2,070	2,557	3,540
% of student body	0.3	0.3	0.3	0.4	0.4	0.5	0.6
Tertiary institutions at accreditation levels 3-4, individuals	917	1,026	1,166	1,441	1,648	2,108	2,522
% of student body	0.1	0.1	0.1	0.1	0.1	0.2	0.2

5. Work being done by the social services and the non-governmental movement for the disabled

At the organizational level, the optimal model for solving the problems of the disabled (including children with disabilities) is being implemented via an informal, constructive partnership between government institutions and other agencies that directly represent the interests of corresponding social groups – including the disabled.

The system of specialized social services for young people, the main operating strategy of which today is one of gradually abandoning charity work in favour of social-psychological rehabilitation, is acquiring great importance. This work is coordinated by Ukraine's National Centre, and regional, city, and district social services for young people. In spite of a short period in which they have been operating (from 1995 on), they have acquired a great deal of experience in this field. In 2001, these agencies offered more than twice as many services, as compared to 1995, for the social support of children and young adults with special needs. The social services are concentrating their operations on rendering social-pedagogical assistance to families with disabled children and/or adolescents, acting as intermediaries between the disabled and members of their family, teachers, friends, and social institutions. Important lines of their work include: offering consultative assistance on social, psychological, and legal matters; helping the disabled to choose occupation, and find employment; organizing entertainment and opportunities to socialize with others; and creating positive public opinion on issues connected with disability. These trends are making it easier for disabled youth to participate in many areas of society's life. The social services are cooperating with the committees and agencies for social protection and education, employment services, and organizations for the disabled.

Today, the non-governmental organizations for the disabled in Ukraine are an important indicator of the formation of civil society, and its ability to organize itself. Of the 18,000 non-governmental organizations in Ukraine, more than 900 engage mostly in the problems of the disabled, while 38 organizations have disabled people among their members. In addition to the opportunities for realizing civic potential, these non-profit organizations provide jobs for certain categories of people and offer important social services to the disabled, thereby facilitating the creation of favourable conditions for people with limited physical abilities to take part in normal life. In most cases, it is through these organizations that business structures and international donors contribute funds for the implementation in Ukraine of targeted social projects.

In drawing up the annual State Budget, funds are regularly earmarked for the financial support of non-governmental organizations for the disabled and their businesses. The government supports the charter activity of non-governmental organizations for the disabled. The amount of funds allocated for the financial support of non-governmental organizations for the disabled and for veterans in 2002 was set in the State Budget at 14.7 million *hrivnas* – 4.6 million more than in 2001.

6. Conclusions and forecasts

The analysis of the situation of disabled children in Ukraine conducted in this survey shows that the individuals falling into this category have certain rights and guarantees in the areas of:

- Pensions and social security payments;
- Medical assistance and provision with prostheses and orthopaedic appliances;
- Social assistance and social services;
- Pre-school, secondary, vocational-technical, and higher education;
- Psychological support and vocational guidance;
- Early social and pre-vocational rehabilitation;
- Social rehabilitation in the workplace and in one's chosen occupation, and help in finding a job.

In Ukraine, however, conditions still exist that make it difficult for the disabled to exercise their rights completely, and do not allow them to participate in the life of society fully and comprehensively – in particular, as a result of disabled individuals' limited access to basic facilities, including housing, transport, education, employment and culture; and of the lack of programmes for living independently among others with the assistance of social workers, and of family support programmes that provide care (temporary or in time of crisis) for disabled children. Certain rights of the disabled are difficult for them to enjoy due to the insufficient financing (and the disproportionate financing) of institutional care, and programmes for offering individual social services. This is one reason why large-scale programmes have not yet been drawn up that might regulate all aspects of improving government policy towards disabled children. The development of such programmes is especially needed, since the year 2003 has been declared the Year of People with Disabilities by the Council of Europe.

APPENDICES

The information used in the Appendices is based solely on the number of disabled individuals registered in the Ministry of Health system. The healthcare facilities run by the Interior Ministry, the Ministry of Defence, the National Security Service, and the Prosecutor General's Office, where no records according to type of illness, age, and place of residence are being kept, have not been included. However, considering that the Ministry of Health's statistics encompass virtually all individuals with disabilities, and that the structural indicators correspond to those for Ukraine nationwide, their use is entirely proper.

In this connection, it must be emphasized that, due to certain shortcomings in the methods for calculating the total number of disabled persons, the data from the Ministry of Health and the Ministry of Labour on the number of disabled individuals registered and drawing disability pensions vary. The data from the Ministry of Labour have been used in the statistical file, while Health Ministry data have been used in the appendices that analyze the breakdowns according to type of illness, age, and place of residence.

Distribution of disabled children under 16, by diseases

Table 1

	Total, thous. persons									
	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Total	112.1	121.8	130.2	135.4	141.1	146.9	152.2	150.3	149.7	147.2
Including those afflicted with:										
- Infectious and parasitic diseases	-	-	-	-	-	-	-	-	0.3	0.4
Of these:										
- Tuberculosis	0.1	0.1	0.1	0.1	0.1	0.2	0.2	0.2	0.2	0.2
- Tumors	2.3	2.8	3.1	3.4	3.7	4.0	4.2	4.4	4.4	4.4
- Endocrine system diseases, digestive disorders, metabolic disorders	4.3	4.8	5.2	5.6	5.9	6.2	6.7	6.8	7.0	7.1
- Diseases of the blood, hemopoietic organs, and certain disorders of the immune system	1.1	1.3	1.4	1.5	1.7	1.7	1.8	1.8	1.8	1.7
- Mental and behavioural disorders	35.8	32.4	31.3	29.7	28.5	28.0	27.4	24.9	24.4	23.6
- Diseases of the nervous system	49.0	53.2	56.7	58.8	60.3	62.2	63.1		36.2	34.9
								37.6*		
Of these:										
- Cerebral paralysis	22.8	23.4	24.4	24.3	24.6	24.1	23.6	22.3	21.3	20.2
- Diseases of the eye and its appendages	5.8	7.3	8.1	8.9	10.0	10.7	11.5	11.8	11.5	11.3
- Diseases of the ear and mastoid process	11.5	13.1	13.1	13.6	13.0	13.4	13.0	11.9	11.2	10.6
- Diseases of the blood circulation system	1.3	1.4	1.3	1.4	1.5	1.6	1.6	1.6	1.5	1.4
- Diseases of the respiratory organs	3.2	4.3	5.2	6.0	6.8	7.3	7.8	8.0	8.0	7.7
- Diseases of the digestive tract	0.9	1.1	1.2	1.5	1.7	1.8	2.0	1.9	1.9	1.9
- Diseases of the urogenital system	1.2	1.6	2.0	2.3	2.8	3.0	3.3	3.2	3.2	3.0
- Diseases of the skin	0.2	0.4	0.5	0.6	0.7	0.9	0.8	0.8	0.8	0.8
- Diseases of the osteomuscular system	3.1	3.4	4.1	4.6	5.2	5.6	6.3	6.7	6.9	7.0
- Congenital defects	9.6	14.5	16.9	18.8	20.8	22.8	25.1	26.6	28.1	29.0
- Injuries and poisoning	-	0.7	1.1	1.1	1.4	1.6	1.9	2.2	2.5	2.5

* Following revised International Classification of Diseases-10, diseases of the eye and ear have been excluded from the category of diseases of the nervous system and sensory organs since 1999, and placed in their own separate category.

Table 1 (continued)

	per 10,000 children of corresponding age									
	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Total	96.3	105.9	145.5	123.1	132.1	141.5	154.7	156.4	162.9	162.9
Including those afflicted with:										
- Infectious and parasitic diseases	0.4	0.4
Of these:										
- Tuberculosis	0.1	0.1	0.1	0.1	0.1	0.1	0.2	0.2	0.2	0.2
- Tumors	2.0	2.4	2.8	3.1	3.5	3.8	4.2	4.4	4.8	4.8
- Endocrine system diseases, digestive disorders, metabolic disorders	3.7	4.2	4.6	5.2	5.6	6.0	6.7	7.1	7.6	7.7
- Diseases of the blood, hemopoietic organs, and certain disorders of the immune system	0.9	1.1	1.2	1.4	1.6	1.7	1.8	1.9	1.9	1.9
- Mental and behavioural disorders	30.7	28.2	27.8	27.0	26.7	26.9	27.3	25.9	26.5	25.6
- Diseases of the nervous system	42.1	46.2	50.3	53.4	56.5	59.9	62.9	39.2	39.4	38.0
Of these:										
- Cerebral paralysis	19.6	20.3	21.6	22.1	23.1	23.2	23.5	23.2	23.1	22.0
- Diseases of the eye and its appendages	5.0	6.3	7.2	8.1	9.4	10.3	11.5	12.3	12.5	12.3
- Diseases of the ear and mastoid process	12.4	12.2	12.9	13.0	12.4	12.2	11.5
- Diseases of the blood circulation system	1.1	1.2	1.2	1.2	1.4	1.5	1.6	1.6	1.6	1.6
- Diseases of the respiratory organs	2.7	3.7	4.6	5.5	6.3	7.1	7.8	8.3	8.7	8.4
- Diseases of the digestive tract	0.8	1.0	1.1	1.4	1.6	1.8	2.0	2.0	2.1	2.1
- Diseases of the urogenital system	1.0	1.4	1.8	2.1	2.6	2.9	3.3	3.3	3.5	3.2
- Diseases of the skin	0.2	0.3	0.4	0.5	0.6	0.9	0.8	0.9	0.9	0.9
- Diseases of the osteomuscular system	2.7	3.0	3.6	4.2	4.8	5.4	6.3	6.9	7.5	7.6
- Congenital defects	8.2	12.6	15.0	17.0	19.5	22.0	25.0	27.7	30.6	31.5
- Injuries and poisoning	...	0.6	1.0	1.0	1.3	1.5	1.9	2.3	2.7	2.8

Distribution of disabled children under 16, by age

Table 2

	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Total, thous. persons	112.1	121.8	130.2	135.4	141.1	146.9	152.2	150.3	149.7	147.2
Including those:										
-under 3	8.2	9.3	8.8	8.2	8.3	8.5	8.6	8.2	8.0	8.0
% of overall total	7.3	7.6	6.8	6.1	5.9	5.8	5.7	5.5	5.4	5.4
- 3-6 years old	21.0	23.9	24.8	25.1	24.8	24.6	24.8	24.4	23.9	23.2
% of overall total	18.7	19.6	19.1	18.5	17.6	16.8	16.3	16.2	16.0	15.8
- 7-13 years old	61.0	66.2	72.9	77.3	82.1	85.4	88.9	87.2	86.1	83.8
% of overall total	54.4	54.3	56.0	57.1	58.2	58.1	58.4	58.0	57.5	56.9
- 14-15 years old	21.9	22.5	23.6	24.8	25.9	28.4	29.9	30.6	31.7	32.2
% of overall total	19.6	18.5	18.1	18.3	18.3	19.3	19.6	20.3	21.1	21.9

Distribution of disabled children under 16, by place of residence

Table 3

	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001
Total, thous. of persons	112.1	121.8	130.2	135.4	141.1	146.9	152.2	150.3	149.7	147.2
Of these:										
- Living (with their families) in the area served by therapeutic-preventive institution	79.1	93.9	102.9	109.3	115.8	122.2	129.2	131.8	132.5	131.8
% of overall total	70.6	77.1	79.0	80.7	82.1	83.2	84.9	87.7	88.5	89.5
- Living in a Ministry of Health infant home	1.8	1.5	1.5	1.6	1.6	1.4	1.3	1.2	1.0	1.0
% of overall total	1.6	1.2	1.2	1.2	1.1	0.9	0.9	0.8	0.7	0.7
- Living in specialized children's homes or residential schools under the Ministry of Education	22.9	19.9	19.2	18.4	17.5	17.6	16.5	12.4	11.4	9.7
% of overall total	20.4	16.3	14.7	13.6	12.4	12.0	10.8	8.3	7.6	6.6
- Living in children's residential homes under the Ministry of Labour and Social Policy	8.3	6.5	6.6	6.1	6.2	5.8	5.2	4.9	4.9	4.7
% of overall total	7.4	5.4	5.1	4.5	4.4	3.9	3.4	3.2	3.2	3.2