

Disability in Children as a Medical and Social Problem

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Abstract The review article is devoted to the analysis of scientific literature and legal documents concerning the state of children's health, childhood disability, medical and social assistance to children with disabilities and people with disabilities. The article describes the main causes of disability, risk factors, and measures to prevent childhood disability, which are the main problems of the pediatric health care system. This article reveals the medical, social and economic problems of early diagnosis of diseases acquired in the early stages of childhood development, congenital and hereditary diseases leading to childhood disability. Ways to eliminate the problems of these diseases at an early stage and solve existing problems in disease prevention were also analyzed. The main directions of measures to improve medical and social assistance to children with disabilities are revealed.

Keywords Child disability, Medical and social assistance, Rehabilitation, Prevention

From the standpoint of today, the priority direction of the social policy of any state is to focus on healthcare in general and the protection of motherhood and childhood in particular. Indicators of disability among children have close relationships with the socio-economic, scientific, technical and cultural standard of living of the population. Families with children with disabilities or disabilities need enhanced primary health care, and this is achieved by improving medical, social and economic assistance to this category of the country's population [22]. The problem of childhood disability is becoming increasingly relevant and significant, this is manifested by an increase in publications related to this topic around the world. Disability, being a kind of indicator of health status, reflects the effectiveness of state and non-state measures of therapeutic assistance to children with disabilities, as well as prevention disability of the child population [4]. Disability is caused by changes in health, the presence of severe and gross disorders of the somatic, psychomotor and psychoneurological development of the child. Consequently, global measures in the healthcare system should be primarily aimed at preventing disability in the child population of a particular country [10].

The policies of democratic countries in the field of children's health today are aimed at reforming the healthcare system, focused on the social aspect, designed to provide qualified and personalized care to patients, and ultimately improve the quality of life of people with disabilities and people with disabilities, especially among children. The development of decisions that affect the situation of disabled children is closely related to data on the epidemiology and

structure of childhood disability, and the dynamics of these indicators [20].

Olusanya B. O. states that due to the lack of clear global data on indicators of childhood disability and the number of children with disabilities, this situation is often interpreted incorrectly, that is, as an insufficiently important or serious problem for modern healthcare, not only local, but also, especially on a global scale. The lack of tools to refine territorial disability indicators for generalization at the global level causes a problem for analysis [1,42]. Researchers from near and far abroad have published systematic reviews and meta-analyses on disability indicators, dedicated to individual types, conducted using various methodological approaches, in countries with different burdens of disability and income levels. However, their generalization does not have a sufficient evidence base to substantiate initiatives to provide assistance and prevent disability in the child population [9,27]. This determines the tendency of politicians and governments to choose such alternative approaches to analyzing the global burden of disability, such as computer statistical modeling [29,48,57].

By the beginning of the 21st century, the World Health Organization (WHO) proposed that states use the International Classification of Functioning, Disability and Health to determine disability acquired during life [60]. At the same time, under the auspices of the United Nations (UN), the Washington Group on Disability Statistics was formed, which subsequently developed disability criteria in accordance with the International Classification of Functioning, Disability and Health [37,38].

The Convention on the Rights of Persons with Disabilities was first formulated in 2006, providing the first definition for children with disabilities. According to the convention, a disabled person is a child aged 18 years or younger who suffers from long-term physical, mental, intellectual or

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sensory impairments, the presence of which creates a barrier to the child's full and equal participation in public life on an equal basis with others" [26]. That same year, UNICEF estimated 150 million children were disabled. However, this assessment was not accompanied by a detailed description of the methods for examining the child population for disabilities; the age aspect was not taken into account, as well as residence in developed or developing countries, which raised doubts among the heads of governments of the world community [54].

WHO in 2011 published the first report on the burden of disability in the world, according to which 93 million children aged 0 to 15 years had moderate and/or severe disabilities, while 13 million children suffered from severe disabilities [61]. WHO experts conducted an analysis based on statistical modeling, but the number of sources on the global burden of disease, injury and risk factors was limited, data were collected before 2004, and children with mild but functionally disabling impairments were not included [40,60]. Also, the WHO expert report did not indicate the proportion of disabled children and children under 5 years of age who are likely to have a better chance of being cured and returning to a normal life with adequate and early interventions. However, WHO presented its report to UNICEF with a number of reservations [55]. A number of publications before 2020 devoted to childhood disability refer to the above report. In 2020, based on data from 2017, global data were updated [33,43,52].

In 2016, UNICEF, together with the Washington Group, defined criteria for a child functioning module that was recommended for regular cluster surveys on a number of indicators globally. In 2021, UNICEF reported that data from 43 countries and 60 regions were compiled, covering 84% of the world's child population, while the obligatory condition was the involvement of at least 50% of the child population of each country in the world [36,53].

A disabled person is a person who has persistent impairments in the functioning of the body, which are provoked by pathological conditions, injuries or other factors leading to limitation of life activity, requiring social assistance and protection. It is well known that the limitation of life activity is understood as a total or partial loss by an individual to perform activities related to self-service, socially useful work, physical, psychological, educational and social activity [1].

According to Miller A. R. and a number of other authors, the term disability is applicable to children 0-18 years old, has gradations in the form of a disability category, as well as a disability group. The group is determined based on the degree of impairment of body functions [23,28,39].

In post-Soviet countries, classifying a child as disabled is the prerogative of federal medical and social examination institutions [3,11,56].

The list of pathological conditions classified as disabilities includes mental, speech, neurosensory and static-dynamic disorders. In addition, these are disorders of the cardiovascular, urinary system, respiratory and gastrointestinal tract, endocrine and metabolic glands, hemostatic and immune disorders,

skin pathology, as well as malformations of human appearance [8,41].

Cieza A. in his works he once again states that in order to establish disability for a child or adolescent before reaching 18 years of age, it is necessary to have a persistent impairment of health in the range of 40-100%, which is caused by pathological conditions of internal organs, injuries, developmental defects leading to limitation of various aspects of life activity, requiring social protection measures [24].

To summarize, we can say that the cohort of disabled children consists of children with various pathologies, injuries, developmental defects, having impaired functioning of individual body systems or their combined damage, the severity of which varies widely and limitations in life activity of varying degrees of severity, in need of social protection states.

In recent years, the attention of many scientists has been focused on children with disabilities, who, according to the report of the European Academy for the Study of Childhood Disability, are represented by a significant number - 8% of the entire child cohort of the population. Olusanya B.O. argues that it is this group that is the source of the formation of a future cohort of children with disabilities [42,52]. However, in most cases, children with disabilities are left out of social support and assistance in treatment.

According to WHO, disabled children make up 2-3% of the total child population worldwide [59].

UNICEF, based on household analysis and in 2021, submitted a report according to which the global burden of disability is represented by the following figures: 28.9 million (4.3%) children aged 0-4 years, 207.4 million (12.5%) children aged 5-17 years and 236.4 million (10.1%) children aged 0-17 years. Children and adolescents with moderate and/or severe disabilities were taken into account. More than half of children with disabilities live in sub-Saharan Africa (29.6% or 69.9 million) and South Asia (27.3% or 64.4 million). West and Central Africa is home to 58.7% (28.9 million) of children with disabilities. The highest incidence of disability was found among the child population of the countries of the Middle East and North Africa (13.1%), the lowest (5.5%) was registered in the child population of the countries of Europe and Central Asia. It is also important that 12.2% of all children with disabilities are children aged 0-5 years. Based on the fact that 10.1% of the world's children have some degree of disability, UNICEF predicts that approximately 266 million children and adolescents aged 0-18 years will have a moderate or severe disability or limited ability [53].

In addition to UNICEF, the burden of disability in the global child population was studied by a global bank. It estimates that in 2019 there were 49.8 million (7.5%) children under 5 years of age, 241.5 million (12.6%) children aged 5-18 years, and 291.4 million (11.3%) of children under 0-18 years of age with disabilities of varying severity [30]. Countries in the South Asian region (33.8% or 98.5 million) and sub-Saharan Africa (20.5% or 59.8 million) accounted for more than half of the children with disabilities.

West and Central Africa accounts for 53.2% (31.7 million) of children with disabilities in sub-Saharan Africa. The highest prevalence of children with disabilities (13.6%) was observed in South Asia, and the lowest prevalence (8.9%) was observed in Europe and Central Asia. Children under 5 years old made up 17.1% of all disabled children [30,32,51].

According to Sabariego C. with co-authors, the share of disabled children corresponds to 4.9% of the entire population of children, in the UK - 2.6%, in the USA, about 4.0% of the aged child population is recognized as disabled due to various pathological conditions, injuries or developmental defects that limit life activity up to 18 years [34,46].

In 2020, 0.1 million people (0.2% of the population under the age of 18) were recognized as disabled children in the CIS countries. In Kyrgyzstan and Tajikistan, childhood disability is 7.2-9.4 per 100,000 children in the country, in Armenia this figure is 14.1-15.4, in Kazakhstan, Belarus and Moldova the figure ranges from 19.3 to 23.8, in Azerbaijan – 31.2 to 45.6 [18].

In the Russian Federation, the disability rate among children is 24.1-28.7 per 100,000 children in the country. The number of disabled children tends to increase. A number of Russian pediatric researchers note that in 2016, 617.0 thousand children with disabilities were registered, in 2017 the figure increased to 636.0 thousand children, and in 2018 it amounted to 651.0 thousand children aged 0-18 years. In 2019, Rosstat reported on 670.1 thousand disabled children; in 2020, this number increased to 687,718 people, which is 13.7% higher than in 2015 [2,18,19,22].

According to Yakovleva T.V., in 2022, in the structure of childhood disability, children 0-7 years old make up 45%, children aged 8-14 years old also make up 45%, and teenagers 15-17 years old make up only 10.0%.

The primary disability cohort is dominated by children aged 0–3 years, while children aged 8–14 years dominate among repeat examinations [22].

In studies of children with disabilities, as well as disabled children suffering from severe disorders, Albitsky V.Yu. et al. found that the structure of morbidity due to disability is dominated by pathology of the nervous system (47.5%); followed by mental disorders (28.7%); then – malformations and deformations, as well as chromosomal pathology (12.2%) [1].

According to Batysheva T.T., the pathology of the nervous system in children, leading to limitations and disability, is represented mainly by cerebral palsy, perinatal brain damage and epilepsy. These pathological conditions lead to the development of motor and cognitive disorders that are life-threatening to the child [6]. Namazova-Baranova L.S. et al. indicate that perinatal lesions of the central nervous system during prematurity in 65–85% of cases inevitably lead to disability [14]. Among mental pathologies, the most frequently disabling factors are psychosis, mental retardation, and autism. Congenital malformations are represented by anomalies of the cardiovascular and nervous systems, chromosomal diseases. Malignant tumors in children and endocrine pathology are the cause of disability in 20% of all

cases of the entire contingent of disabled children [4,10,20]. According to Tichenor M. severe congenital anomalies in 75.2% of cases lead to inevitable disability [50]. Studying congenital anomalies and chromosomal disorders Leonardi M. in 2022, showed that lesions of the central nervous system during the period of antenatal development subsequently manifest as disability due to severe retardation in the psychomotor development of such children [35].

In Russia, in 2021, a federal law was adopted on the protection of the health of citizens and the provision of all types of medical care to persons suffering from orphan (rare) diseases. This legal document guarantees the state provision of such patients with medicines and specialized medical nutrition products [17]. According to the Federal Register created by this law, there has been an increase in the number of children with disabilities and children with disabilities. By mid-2021, the register recorded more than 270 pathological conditions leading to disability in children. According to L.S. Namazova-Baranova's classification of newborns with low, very low and extremely low birth weight as a sign of live birth resulted in an increase in newborns with disabling disorders [14]. These include Patra K. refers to intracranial hemorrhages, Vincer M. J. – organic pathology of the brain, agenesis or dysgenesis of the lungs, Sadovnikova N.N. and others – congenital retinopathy of prematurity and Gaucher disease [5,7,12,15,16,21,44,58].

In the Republic of Uzbekistan, despite the growth of the total population in the last decade, the share of childhood disability averages 2.2% of the country's entire child population with a clear downward trend. Kasimova D.A., when studying this problem, indicates that the disability rate was 75.8 per 10,000 children. In more than half of the cases, childhood disability (61.2%) is caused by congenital pathology. Childhood disability in the republic is represented by 5 categories of pathologies: pathology of the nervous system, congenital anomalies, pathology of the musculoskeletal system, pathology of the inner ear and mastoid process of the temporal bone of the skull, mental disorders. Among all causes of childhood disability, the above conditions account for 78.5% [11]. To summarize, it can be stated that in the Republic of Uzbekistan every third child with an established disability is aged 0-6 years, the structure is dominated by congenital causes of disability, occupying leading positions in all age groups [62].

It is well known that children's disabilities are often provoked by both traumatic conditions and insufficient level of timely diagnostic, therapeutic and rehabilitation measures [25].

Mortality rates in the group of children 0-5 years old are a direct indicator of social, economic, medical and environmental problems of the state and society as a whole. However, only a few publications are devoted to the study of probable disability if an injury occurs before the child reaches the age of five [31,45,49]. Available literature data indicate that, globally, the probability of a child becoming disabled before reaching the age of five is an order of magnitude higher than the probability of death (376.9 versus 38.4 for every 1000 live births) in 2019 [47].

In general, in the world, as in most countries in particular, some progress has been made in addressing issues related to the needs of children with disabilities and children with disabilities, starting from an early age. However, analysis of data on the prevalence of childhood disability by UNICEF and the World Bank once again emphasizes the need to improve appropriate policy, social and economic interventions for this cohort of the population.

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