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CHARACTERISTICS OF DISABLED CHILDREN BORN WITH CONGENITAL ANOMALYS IN FERGANA REGION

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Abstract
Congenital anomalies are structural or functional defects present at birth. Such conditions can lead to physical or mental disabilities in children. The impact of congenital anomalies varies greatly depending on their type and the general health of the child. This article examines the specific characteristics of children with disabilities born with congenital anomalies, their difficulties and methods of supporting their development, and the current state of examination and analysis of children with disabilities in the Fergana region.

Keywords: Congenital anomalies, hereditary factors, infection, children with disabilities, polyorgan, polymorphic, pathology, hyperactivity, autism, skeletal, craniofacial, neurological, septal defects, deformation, Down syndrome, cognitive, orthopedic supports, stigmatization, inclusive education, individual assistance, integration, optic nerve atrophy, musculoskeletal diseases, connective tissue, injury, malignant neoplasms, poisoning.

Introduction

Congenital anomalies are structural or functional differences in a child's body or genetics that are present before birth. Approximately 3 percent, or one in 30 children, are born with a congenital anomaly. The anomalies can affect various parts of the body, including the heart, brain, limbs, and internal organs. The main causes of anomalies can be hereditary factors, exposure to certain substances during pregnancy, infections, or a combination of factors.

Childhood disabilities are a major problem in modern society. [13] According to a report by the World Health Organization, one billion people worldwide, or 15 percent of the world's population, suffer from disabilities. 110–190 million people (2% of the world's population) have serious or severe disabilities in their daily lives.[5] There is a growing trend of disability in children worldwide. Gender, age, and place of residence have a certain influence on the formation of disability. There are several causes of disability. In recent decades, from 2010 to 2016, the level of disability among children in Russia has been steadily growing. The number of children with disabilities has increased several times. Every year, the number of young patients with multi-organ,

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polymorphic, and combined pathologies is increasing. All this necessitates the improvement of health, rehabilitation, and correctional work with children with disabilities in special and general schools, preschool institutions, as well as specialized rehabilitation centers, children's clinics, hospitals, sanatoriums, and especially in families. [13]

Developmental disabilities were reported in 1 in 6 children in the United States between 2006 and 2008. The number of children with specific developmental disabilities (autism, attention deficit hyperactivity disorder, and other developmental delays) is increasing, requiring more health and educational services.[1]

1. Physical features

Children with congenital anomalies often exhibit specific physical features depending on the organ or system affected:

Skeletal anomalies: For example, deformities of the limbs, feet, or spinal abnormalities such as scoliosis.

Craniofacial anomalies: Conditions such as cleft lip, cleft palate, or craniosynostosis can affect the face and skull.

Neurological conditions: Microcephaly or hydrocephalus can change the size and structure of the brain and skull.

Internal organ defects: Some children are born with heart defects (such as ventricular septal defects) or kidney defects, which can impair organ function.

2. Developmental characteristics

Congenital anomalies often affect children's developmental milestones:

Delayed abilities: Physical abnormalities such as limb deformities can delay sitting, walking, or grasping.

Cognitive delays: Neurological problems, such as those associated with Down syndrome, can lead to delayed intellectual development.

Speech and language problems: Craniofacial abnormalities or hearing impairments can affect language acquisition and communication skills.

Emotional and social problems: Children with visible anomalies may experience difficulties with self-esteem and social interactions due to stigmatization or bullying.

3. Medical Needs

Children with disabilities who have congenital anomalies often require specialized medical care:

Surgical Intervention: Many anomalies, such as cleft lip or heart defects, may require corrective surgery early in life.

Rehabilitation Services: Physical, occupational, and speech therapy are essential to improve mobility, function, and communication.

Assistive Devices: Orthopedic braces, hearing aids, or a wheelchair may be necessary to increase independence.

Chronic Care Management: Conditions such as congenital heart defects may require lifelong monitoring and treatment.

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4. Behavioral and Psychological Characteristics

Resilience: Many children with disabilities demonstrate remarkable resilience and adaptability despite their challenges.

Emotional Vulnerability: Experiences of pain, exclusion, or dependency can lead to anxiety, depression, or behavioral problems.

Strong family ties: Children with disabilities often develop close relationships with their caregivers because they are often dependent on support.

5. Social and educational needs

Inclusive environments and adapted educational plans are essential for children with congenital anomalies:

Inclusive education: Access to schools with supportive learning environments encourages cognitive and social growth.

Individualized support: Individualized educational plans (IEPs) help meet the unique developmental needs of these children.

Community involvement: Participation in social activities and community programs helps with social integration and self-esteem.

6. Role of family and caregiver

Families play a crucial role in the development of children with disabilities with congenital anomalies:

Emotional support: Providing love and encouragement helps build a child's self-confidence and resilience.

Advocacy: Parents often advocate for health care, educational facilities, and social acceptance for their children.

Adaptability: Families may need to adjust their daily routines to meet the child's medical and developmental needs.

Rehabilitation of Children with Disabilities:

• Rehabilitation professionals seeking to increase physical activity in youth with physical disabilities should discuss readiness for change and motivation before addressing any activity/sport.

• Different behavioral change processes are required for youth and their parents, and both are important for achieving physical activity.

• Regular monitoring, and follow-up

• Adolescents should be aware that they may be more willing to be active as they develop greater independence and awareness of the benefits of physical activity.[10]

In 2017, 22 percent of the 680,611 children in the U.S. foster care system had a diagnosis of a disability that required additional or specialized support.[8]

"Participation" in meaningful life activities should be an important intervention goal to address healthy growth and development challenges and to provide opportunities that help young people with disabilities realize their potential throughout their lives.[2]

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Disability status is primarily determined through the use of vulnerability screens that list multiple significant impairments. Recent research suggests the use of the ICIDH and ICF in the development of disability questions. This may be largely due to the guidance in the United Nations Census Recommendations on the use of the ICIDH framework and terminology for the development of disability question(s). The work of the United Nations Statistics Division to improve the international comparability of methods and the use of international standards may increase the use of the ICF in measuring disability. This includes regional training workshops, as well as the work of the newly established Washington DC Group on Disability Measurement.[6]
Disability is defined as a limitation of activity and participation associated with the interaction of functional impairments and supports (personal, mechanical, and environmental/social).[9]
Child disability is a general concept. It includes children with disabilities under the age of 16, receiving social benefits, living in families and the state, and in specialized institutions. Children with disabilities also include children over the age of 16.[11] Childhood disability in Uzbekistan is poorly studied as a socio-economic, medical, and legal concept and is given little importance in organizational relations.[14]

Research Objective

To study and analyze the results of primary surveys. To conduct a comprehensive study of the causes of disability in the Fergana region and to scientifically substantiate the need to improve the quality of care for children with disabilities. [4]

Results

The study showed that since 2015, all primary surveys conducted in Fergana region amounted to 2628. According to the statistical observation method (extracts from reporting data, materials of social protection bodies and regional VTEK), children with disabilities made up 609 (22.8%) of the sampled people in Fergana region. Among them, gender, age and place of residence have a certain impact on the formation of disability. Literature data show that the number of women in the prevalence of disability among different age and gender groups of the population is small. According to the data, 60.8% of children with disabilities from the total number of those sampled are men. The level of disability among men is always higher than among women. Let us pay special attention to the prevalence of disability in urban and rural areas. In urban areas, the share of children with disabilities since childhood is 42.4%, and in rural areas - 57.6%. Of the total number of children recognized as disabled, 75 (12.3%) were recognized as disabled for the first time.
A comparison of the share of children recognized as disabled by disability group shows that:
The share of disabled people in group I is 12.3% (14.7% in cities, 10.5% in rural areas, group II is 56.7% (52.7% in urban settlements, 59.5% in rural areas, 18.9% in group III. (22.5% in cities, 16.2% in rural settlements).
The main factors and reasons that determine the recognition of disabled people for the first time are:
In the composition of the causes of disability, the main causes of disability of group II are mental disorders - 53.6%, ear and mastoid diseases - 23.1%, clinical diseases - 8.9%, malignant neoplasms - 7.1%.

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The main causes of disability of group III are congenital.

Congenital anomalies - 40.0%, eye and their concomitant diseases,[11]. The main cause of visual impairment and disability is optic nerve atrophy. Retinopathy of prematurity is also found in children with disabilities is common and causes significant visual impairment.[7] Musculoskeletal and connective tissue diseases, as well as injuries and poisonings, and some other external causes each accounted for 20%.[11]

Conclusion

Children with congenital anomalies face unique challenges, but with appropriate medical care, educational support, and an inclusive environment, they can make significant progress. A holistic approach that addresses physical, emotional, and social needs is essential for their well-being and integration into society. Collaboration between health professionals, educators, and families plays a critical role in their growth and development.

Thus, the analysis of types of disabilities by social protection agencies and VTEK materials on persons recognized as children with disabilities has allowed us to express some thoughts on these. [11]

References

1. Boyle CA, Boulet S, Schieve LA, Cohen RA, Blumberg SJ, Yeargin-Allsopp M, Visser S, Kogan MD. Trends in the prevalence of developmental disabilities in US children, 1997-2008. Pediatrics. 2011 Jun;127(6):1034-42. doi: 10.1542/peds.2010-2989. Epub 2011 May 23. PMID: 21606152.
2. Imms C, Granlund M, Wilson PH, Steenbergen B, Rosenbaum PL, Gordon AM. Participation, both a means and an end: a conceptual analysis of processes and outcomes in childhood disability. Dev Med Child Neurol. 2017 Jan;59(1):16-25. doi: 10.1111/dmcn.13237. Epub 2016 Sep 19. PMID: 27640996.
3. Kasimova D.A. Prediction of risk and multilevel program of prevention the children invalidity. Methodical recommendations. Tashkent, 9 December. 2011y. -13p.
4. Kasimova D.A. Medical and social aspects of childhood disability and ways to reduce (on materials of Tashkent).//Avtoreferat -2012.
5. Kostanjsek N, Good A, Madden RH, Üstün TB, Chatterji S, Mathers CD, Officer A. Counting disability: global and national estimation. Disabil Rehabil. 2013 Jun;35(13):1065-9. doi: 10.3109/09638288.2012.720354. PMID: 23725494
6. Mbogoni M. On the application of the ICIDH and ICF in developing countries: evidence from the United Nations Disability Statistics Database (DISTAT). Disabil Rehabil. 2003 Jun 3-17;25(11-12):644-58. doi: 10.1080/0963828031000137144. PMID: 12959339
7. Moll A, Orawiec B, Niwald A, Grałek M. Causes of visual disability in children and young adults. Klin Oczna. 2005;107(1-3):93-5. PMID: 16052813.
8. Platt C, Gephart SM. Placement disruption of children with disabilities in foster care. J Pediatr Nurs. 2022 Sep-Oct;66:30-35. doi: 10.1016/j.pedn.2022.05.004. Epub 2022 May 20. PMID: 35605440.

Web of Medicine: Journal of Medicine, Practice and Nursing
webofjournals.com/index.php/5

9. White C. Update on the harmonisation of disability data collection in UK surveys (part 1). Health Stat Q. 2011 Autumn;(51):3-30. doi: 10.1057/hsq.2011.12. PMID: 21894156.
10. Wright A, Roberts R, Bowman G, Crettenden A. Barriers and facilitators to physical activity participation for children with physical disability: comparing and contrasting the views of children, young people, and their clinicians. Disabil Rehabil. 2019 Jun;41(13):1499-1507. doi: 10.1080/09638288.2018.1432702. Epub 2018 Jan 30. PMID: 29382235
11. Астанакулов Д. Й. Анализ впервые признанных инвалидов с детства в ферганской области //Инновации в образовании и медицине. Материалы IV Всероссийской на. – 2017. – С. 233.)
12. Б.М.Маматқулов, Г.С.Авезова, Д.А.Қосимова. Болалар саломатлиги ва хавф омилларини ўрганишда далилларга асосланган тиббиёт усулларини қўллаш. Илмий-услубий қўлланма. Тошкент. 28.10.2011.-15б.
13. Карелина И. Б., Туркина М. В. Психолого-педагогическая абилитация и реабилитация детей-инвалидов //Universum: медицина и фармакология. – 2016. – №. 11 (33). – С. 28-34.
14. Касимова Д.А. Социально-гигиенические факторы риска детской инвалидности. //Бюллетень ассоциации врачей Узбекистана РУз. Ташкент, 2011. №4. –С.27-29.
15. Касимова Д.А. Влияние социально-гигиенических факторов на уровне детской инвалидности (по материалам Чиланзарского района в г. Ташкенте). // Дни молодых учёных. ТМА. Материалы научно-практической конференции магистрантов. Ташкент, 19-20 апреля 2011. –С.107.
16. Касимова Д.А. Возрастно-половые особенности детской инвалидности. // Научный практический журн. Патология. Ташкент-2010. №2-3. -С.132-136.
17. Касимова Д.А. Детская инвалидность важнейший показатель здоровья населения. //Дни молодых учёных. Материалы научно-практической конференции аспирантов, соискателей и магистрантов. ТМА.-Ташкент, 14-15 апреля. 2009 -С. 44-45.
18. Касимова Д.А. Детская инвалидность как медико-социальная проблема в здравоохранении. //Гигиенические проблемы охраны здоровья населения на современном этапе и пути их решения. Материалы научно-практической конференции, Ташкент, 6 марта 2010. -С.155-156.
19. Касимова Д.А. Методологические основы детской инвалидности в г.Ташкенте. //Дни молодых учёных. Материалы научно-практической конференции аспирантов, соискателей и магистрантов. ТМА.-Ташкент. 14-15апреля. 2009 -С.48-49.
20. Касимова Д.А. Некоторые особенности изучения детской инвалидности. //Дни молодых учёных. Материалы научно-практической конференции аспирантов, соискателей и магистрантов. ТМА.-Ташкент, 14-15апреля. 2009 - С.46-47.
21. Касимова Д.А. Основные закономерности динамики детской инвалидности. //Бюллетень Ассоциации врачей РУз.Ташкент, 2012 №1-С.40-42.
22. Касимова Д.А. Прогнозирование риска и многоуровневая программа профилактики детской инвалидности. Научные-методические рекомендации. Ташкент, 9 декабря 2011.-15с.

Web of Medicine: Journal of Medicine, Practice and Nursing
webofjournals.com/index.php/5

23. Касимова Д.А. Пути повышения качества детской инвалидности в условиях первичной медико-санитарной помощи.//Республиканская конференция: «Развитие первичного звена здравоохранения Узбекистана за 10 лет». Ташкент, 06.2010. –С.136.
24. Касимова Д.А. Структура и уровень детской инвалидности (по материалам Мирзо Улугбекского района). // Дни молодых учёных. ТМА. Ташкент,19-20 апреля 2011. -С. 32.
25. Касимова Д.А., Маматкулов Б.М. Медико-социальные аспекты детской инвалидности. Врач-аспирант. Воронеж, 2011 -№ 2,3 (45). -С. 512-516.
26. Маматкулов Б., Азимов Р., Авезова Г., Касимова Д., Инаков Ш. Доказательная медицина как инструмент повышения качества медицинской помощи. //Республиканская конференция: «Развитие первичного звена здравоохранения Узбекистана за 10 лет». Ташкент, 06.2010. -С.132.

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