Executive summary of the public audit report

WHETHER EARLY REHABILITATION SERVICES AND INCLUSIVE EDUCATION MEET THE NEEDS OF CHILDREN WITH DISABILITIES AND ENSURE THEIR SOCIAL INTEGRATION

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DEFINITIONS AND ABBREVIATIONS

Early rehabilitation (ER): integrated assistance to families with children with psychological and social developmental disorders and risk thereof, provided to reduce disability and help the child to integrate into society[1].

Approve: to accept, authorize, allow.

HCE: a healthcare establishment.

Techniques and methods of diagnosis and treatment: a medical science and practical evidence-based document developed by universities, research institutions and physicians' professional associations, which defines the general principles of diagnosis and treatment of health problems and diseases[2].

Inclusive education: a process that ensures the quality of education (learning) for all of its participants, taking into account expectations, peculiarities of educational needs, assistance and service needs of each student and, his or her parents (or guardians), and prevents "dropping off the radar" of the education system[3].

Disability: a long-term health deterioration and decreased level of operational capabilities and participation in social activities, which occurred due to impairment of the structure and functions of a person's body caused by the interaction of adverse environmental factors[4].

PHCC: Primary Healthcare Centre.

CSNEP: Centre for Special Needs Education and Psychology.

Special assistance measures: measures for the fulfilment of special needs, aimed at providing their disabled receiver with equal educational, professional and social opportunities as well as opportunities for full integration into society[5].

Special educational needs (SEN): the need for assistance and services in the education process, whether due to the exceptional abilities of a person, congenital or acquired disorders or adverse environmental factors.

Education assistance: professional assistance provided to students, their parents (or guardians), teachers and education providers aiming at increasing the effectiveness of education.[6].

The child's developmental disorder (CDD): a significant departure from the normal developmental sequence. A disorder may manifest as a physical, cognitive, emotional, or social dysfunction or developmental lag. A developmental disorder should be regarded as a dynamic process influenced by multiple factors.

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[1] Principles of Organization of Early Rehabilitation Services for Children with Developmental Disorders approved by Order No. 728 of the Lithuanian Minister of Health, 14/12/2000 (Annex 1), p. 9.1.

[2] The Republic of Lithuania Law on the Rights of Patients and Compensation of the Damage to their Health No. I-1562 (amended version No. XI-499 of 19/11/2009), 03/10/1996, Art. 2.

[3] The 2014-2016 Action Plan for the Strengthening and Inclusive Education Development of General Education Schools Carrying Out the Primary and Basic Education Programs approved by Order No. V-808 of the Lithuanian Minister of Education and Science, 05/09/2014, p. 17.

[4] The Republic of Lithuania Law on Social Integration of Persons with Disabilities No. I-2004 (amended version No. IX-2228 of 11/05/2004), 28/11/1991, Art. 2

[5] Ibid.

[6] The Republic of Lithuania Law on Education No. I-1489 (amended version No. 1281 of 17/03/2011), 25/06/1991, Art. 2

Child Development Centre (CDC): Children's Hospital, Affiliate Child Development Centre of PI Vilnius University Hospital Santariškių Klinikos.

Children's Rehabilitation Hospital "**Lopšelis**"**:** Branch of Kaunas Clinics of LUHS Hospital Children's Rehabilitation Hospital "Lopšelis".

ERCDD: early rehabilitation of children's developmental disorders.

SUMMARY

The United Nations Convention on the Rights of the Child[7] provides that a disabled child is entitled to a full and proper life, ensuring the child's human dignity, developing his or her confidence and allowing to actively participate in social life, as well as the right, equal to that of healthy children, to live actively, evolve and get education that meets his or her mental and physical powers and preferences. By acceding to this Convention, Lithuania committed to take all legal, administrative and other actions necessary for the implementation of the child's rights.

At the beginning of 2016, there were approximately 14.7 thousand disabled children in Lithuania, requiring comprehensive social, medical and educational services as well as other assistance. In 2015, about 16 million euros were used to implement the measures of the 2013-2019 National Programme for Social Integration of Persons with Disabilities.

The earlier a child is diagnosed with developmental disorders and the quality early rehabilitation services are provided, the greater the chance of avoiding disability that will accompany the child throughout his or her life, or reducing the level of such disability as much as possible. Early rehabilitation helps children to develop independence and integrate into society and education system. At the beginning of 2016, early rehabilitation services were provided by the country's 45 healthcare establishments in 34 municipalities. In 2015, such services were provided to nearly 13 thousand children. Approximately 4 million euros in the Compulsory Health Insurance Fund were used to cover their expenses. However, not all children who needed early rehabilitation services had equal opportunities to receive such services or receive them in a timely and high-quality manner.

Education in general education schools also helps to prepare people with disabilities for independent living and integrate them into public life. According to the Convention on the Rights of Persons with Disabilities,[8] the State must ensure that persons with disabilities are not removed from the general education system because of their disability; that persons with disabilities are provided with the opportunity to get a free, proper and quality primary and secondary education alongside others in the communities, where they reside; that conditions are adequately adapted in accordance with a person's needs; that persons with disabilities receive the necessary support in the general education system. However, the number of the country's special purpose educational institutions and the number of children attending them failed to decrease over the last three years, while the number of children with disabilities in general purpose educational institutions actually decreased.

One of the main conditions of integration of children with disabilities into the general education is the adequate infrastructure of educational institutions. Although between 2000 and 2015 various funding sources invested in municipal educational institutions 503 million euros, the environment adapted or partially adapted to meet the needs of persons with disabilities has not been created in all municipal educational institutions.

These problems led to the National Audit Office taking interest in the social integration of persons with disabilities.

[7] The Convention on the Rights of the Child ratified on 03/07/1995 by the Law on Ratification of the United Nations Convention on the Rights of the Child No. I-983 adopted by the Seimas of the Republic of Lithuania, Art. 23.

[8] The Convention on the Rights of Persons with Disabilities ratified on 27/05/2010 by the Law No. XI-854 adopted by the Seimas of the Republic of Lithuania.

The purpose of the audit was to assess whether the measures of social integration of children with disabilities are effective. The following issues were addressed over the course of the audit:

- whether availability and quality of early rehabilitation services is ensured to children with developmental disorders;
- whether the effective inclusive education of children with disabilities is ensured, including such children into the general education system.

After analysing and assessing during initial investigation the problems related to social integration of persons with disabilities, the focus of the main investigation was the quality of early rehabilitation services and their availability for children with developmental disorders as well as assessment of inclusive education of children with disabilities.

The audit was conducted in the Ministry of Social Security and Labour, the Ministry of Health and the Ministry of Education and Science. In addition, we collected information from 65 healthcare establishments, the National Health Insurance Fund under the Ministry of Health, the State Health Care Accreditation Agency under the Ministry of Health, Institute of Hygiene, the Department for the Affairs of the Disabled under the Ministry of Social Security and Labour, six municipalities (Vilnius, Kaunas, Utena, Telšiai, Šilalė, and Širvintos regions), and 84 general education schools in these municipalities. Additional audit procedures were conducted in Vilnius Region Municipality, Kaunas Region Municipality, Child Development Centre, and Children's Rehabilitation Hospital "Lopšelis".

The audit covered the period from 2013 to 2015.

The following public audit conclusions and recommendations were drawn upon the assessment of the audit findings.

CONCLUSIONS

On quality of early rehabilitation services and their availability for children with developmental disorders

Due to the insufficient availability and quality of early rehabilitation services, the need of children with developmental disorders for such services cannot be assessed objectively, and not all children with developmental disorders are granted such services in a timely and high-quality manner. As a result, the level of children's disability and the risk of its occurrence is not being reduced. Consequently, a successful integration of such children into society and education system cannot be ensured:

1. Waiting lists for both outpatient and inpatient early rehabilitation services are very long. in 2015, the average waiting time for outpatient early rehabilitation services in seven institutions (out of a total of 45 institutions) exceeded the target rate (25 calendar days), and the longest average waiting time (118 calendar days) exceeded the target rate almost fivefold. The average waiting time for inpatient early rehabilitation services (approximately 150 calendar days) exceeded the target rate (60 calendar days) about 2.5 times:

    1.1. Underdeveloped early rehabilitation infrastructure: almost half of the country's municipalities (27) fail to provide outpatient early rehabilitation services. Due to limited availability of outpatient early rehabilitation services, a certain number of children did not receive these services or were prescribed inpatient treatment, although their level of disorder did not require inpatient treatment that is more expensive than outpatient treatment. Inpatient

services are only provided in two healthcare establishments, and the number of places (beds) in these establishments fell from 66 to 60 during the audit period (Subsections 1.1.1 and 1.1.2).

1.2. The development of early rehabilitation services started without a proper assessment of their need; therefore, there is a risk that funds allocated for their development will be used ineffectively and irregular territorial availability of early rehabilitation services will not be remedied, because:

1.2.1. The early rehabilitation services were launched in the reorganized homes for infants with developmental delays located in municipalities with institutions already providing such services (Vilnius and Klaipėda), without harmonizing the 2014-2020 action plan[9] for transition from institutional care to services provided by the family and the community to children with disabilities and children without parental care and the 2014-2023 action plan for reducing healthcare disparities in Lithuania[10]. As a result, irregular territorial availability of early rehabilitation services has not been remedied. In both Šiauliai City Municipality and Alytus City Municipality the use of such services exceeded the country's average rate, so the territorial health insurance funds did not sign a contract for early rehabilitation services with homes for infants with developmental delays located in these municipalities (Subsection 1.1.1).

1.2.2. The issue of transferring the Child Development Centre from the building in critical condition to the premises adapted to the Centre's activities remains unresolved for more than eight years. In the absence of investment in the early rehabilitation service infrastructure strategy, in 2012, the Children's Hospital, PI Vilnius University Paediatric Centre, Consultant Clinic and Affiliate Child Development Centre construction project was developed (the project value being 375.6 thousand euros). However, construction work did not start, because in 2014, at the suggestion of PI Vilnius University Hospital Santariškių Klinikos and the Ministry of Health, the Strategic Committee of the Lithuanian Government decided to reduce paediatric housing of the Children's Hospital from 45 thousand square metres to 15 thousand square metres and abort construction of the Child Development Centre. Therefore, there is a risk that the funds allocated for the project were used inefficiently (Subsection 1.1.2).

1.3. Institutions providing early rehabilitation services lack specialists. The established workload standards are not observed (in 19 out of 20 institutions). Consequently, specialists' workload differs significantly (for example, in 2015 the average number of patients per physician's staff position was 104 to 2448). Not all institutions managed to form a full team of specialists. For example, one institution did not have a psychologist and social worker, one institution did not have a speech therapist or social worker, and 12 institutions did not have a nurse. Children with disorders require services of occupational therapist and special education teacher, but the current legislation does not include such staff positions in the provision of outpatient early rehabilitation services (Subsection 1.1.3).

1.4. The right of children 4 to 7 years of age attending educational institutions to receive integrated outpatient early rehabilitation services has not been secured, because the order of

[9] Approved by Order No. A1-83 of the Lithuanian Minister of Social Security and Labour, 14/02/2014.

[10] Approved by Order No. V-815 of the Lithuanian Minister of Health, 16/07/2014.

the Minister of Health[11] indicates that integrated outpatient early rehabilitation services are only provided to children at this age if they do not attend educational institutions. Therefore, not only one third of 34 surveyed institutions providing early rehabilitation services were not providing integrated outpatient services to children 4 to 7 years of age attending an educational institution, but educational institutions also could not provide such services due to shortages of specialists (Subsection 1.4).

1.5. Three institutions providing early rehabilitation services (out of 45) failed to provide advanced multidisciplinary consultations, because the Ministry of Health did not establish or approve a base price and payment procedures for this service (Subsection 1.3).

2. No sufficient conditions required for the provision of early rehabilitation services were insured, because:

2.1. The Ministry of Health failed to assess the need for diagnostic tests for children with developmental disorders, the list of used diagnostic tests for children with developmental disorders has not been revised and updated for more than 15 years[12]. More than one third of 44 surveyed institutions providing early rehabilitation services do not have tests necessary for properly diagnosing a child with developmental disorders; one fourth of the said institutions considers the tests available unsuitable for children's various age groups; and four institutions indicated that some of the tests used are inaccurate and not reliable enough. We also discovered that, in addition to the mandatory tests, six institutions use tests that are more relevant, in their opinion; however, these tests have not been adapted for use in Lithuania (Subsection 1.2).

2.2. At a national level, no standards for the diagnosis and treatment of children with developmental disorders (methodologies / procedural descriptions) have been prepared and approved (Subsection 1.2).

On inclusive education for children with disabilities

3. Children with disabilities and special educational needs have not been provided with the opportunity to get a proper and quality primary and basic education in general education schools alongside others in the communities, where they reside. These children are insufficiently prepared for independent life. Over the past three years, the number children with disabilities in the country's special purpose educational institutions increased from 35% to 38% of all children with disabilities attending educational institutions. Accordingly, the number children with disabilities in general purpose educational institutions decreased from 65% to 62%. The number of special purpose educational institutions also increased (from 72 to 74). Not all children with disabilities are included into the general education system, because:

3.1. The tools and measures for development of inclusive education specified the 2014-2016 Action Plan for the Strengthening and Inclusive Education Development of General Education Schools Carrying Out the Primary and Basic Education Programs[13] have not been implemented (Section 2).

[11] Principles of Organization of Early Rehabilitation Services for Children with Developmental Disorders approved by Order No. 728 of the Lithuanian Minister of Health, 14/12/2000, p. 7.

[12] Approved by Order No. 728 of the Lithuanian Minister of Health, 14/12/2000.

[13] Approved by order No. V-808 of the Lithuanian Minister of Education and Science, 05/09/2014.

3.2. In four municipalities (out of six analysed), 56% or less of the environment of educational institutions (the smallest part in Kaunas Region Municipality (26%) and Telšiai Region Municipality (39%)) were adapted (or partially adapted) to the needs of persons with disabilities (Subsection 2.1.1).

3.3. More than half of the general education schools (out of 84 surveyed) lack special pedagogical and special assistance workers; only one third of specialists of the surveyed institutions, who work with children with disabilities and special educational needs, participated in the 2013-2015 improvement programme (Subsection 2.1.2).

3.4. One third of 84 surveyed general education schools lack methodological assistance of the National Centre for Special Needs Education and Psychology, one tenth lack assistance of the Municipal Education Department; a large majority (92%) of institutions does not follow the methodologies (recommendations) publicly announced by the National Centre for Special Needs Education and Psychology; 52% of the institutions lack special educational and academic measures (Subsection 2.2).

3.5. In five municipalities (out of six), compulsory education of all pre-primary and pre-school children raised at social risk families is not ensured. Municipalities failed to provide good reasons why 15 disabled children from the social risk families have not been specified and provided with compulsory education (Subsection 2.3).

4. In the field of education, there is a sufficient lack of positive public attitudes towards disabled people as well as lack of coverage while planning and implementing the measures aiming to increase tolerant attitudes towards people with disabilities (Subsection 2.4):

4.1. In 2013-2016, the Ministry of Education and Science and audited municipalities failed to plan or implement any concrete measures aiming to increase tolerant attitudes towards people with disabilities.

4.2. During the school year of 2015-2016, 16% of general education schools failed to plan measures aiming to increase tolerant attitudes towards people with disabilities and 13% of general education schools failed to implement such measures (out of 82 surveyed).

RECOMMENDATIONS

To the Ministry of Health

In order to reduce the risk of disability in children with developmental disorders and the level thereof, to successfully integrate them into society and educational system, the availability of early rehabilitation services to children with developmental disorders and their parents must be ensured. The following are, therefore, necessary:

1. Planning and implementing specific measures (such as formation of mobile teams, etc.), so that outpatient early rehabilitation services are available to children from municipalities, where such services are not provided (Conclusion 1.1).
2. Assessing the need for inpatient early rehabilitation services (number of corresponding institutions and their patient capacity) and providing specific measures to improve the accessibility of these services (Conclusion 1.1).
3. Taking immediate concrete measures to ensure that the Child Development Centre provides its services in the premises adapted to its activities, i.e. providing the Centre with temporary premises, repairing the existing premises, or specifying and implementing other measures to ensure the availability and quality of services provided by the Child Development Centre (Conclusion 1.2.2).
4. Changing requirements of legal acts, in accordance with which:
   4.1. teams of specialists providing outpatient early rehabilitation services should include staff positions of occupational therapist and special education teacher (Conclusion 1.3);
   4.2. a base price of early rehabilitation secondary advanced multidisciplinary consultation and payment procedures for this service should be determined (Conclusion 1.5);
   4.3. integrated outpatient early rehabilitation services should be provided to children 4 to 7 years of age attending an educational institution (Conclusion 1.4).
5. Preparing the recommendations (guidelines) regarding workload of professionals providing early rehabilitation services to children with developmental disorders (Conclusion 1.3).

In order to ensure the quality of early rehabilitation services, it is necessary:

6. to prepare and approve standards for the diagnosis and treatment of children with developmental disorders (methodologies / procedural descriptions) (Conclusion 2.2).
7. to identify a nationwide need for diagnostic tests for children with developmental disorders and, taking the results into account, initiate the development or acquisition of missing tests as well as their adaptation for use in Lithuania (Conclusion 2.1).
8. to publicly announce methodologies (procedural descriptions) for the diagnosis and treatment of children with developmental disorders.

To the Ministry of Education and Science

In order to provide children with disabilities and special educational needs with the opportunity to get a proper and quality primary and basic education in general education schools alongside others in the communities, where they reside, and ensure a successful integration of these children and their families into society, it is necessary:

9. to provide and implement concrete tools and measures for strengthening and development of inclusive education in general education schools implementing the primary and basic education programmes; to establish interim implementation deadlines and assessment criteria values for the period 2017 to 2022 (Conclusion 3.1).
10. to provide and implement concrete measures:
    10.1. in order to adapt the environment of educational institutions to the needs of children with motor and other disabilities (Conclusion 3.2);
    10.2. in order to ensure a sufficient number of staff positions of education aides in schools, to differentiate education voucher funds in accordance with the level of special educational needs (Conclusion 3.3).

11. Assessing the need for methodologies (recommendations) that aim to help teachers organize quality education for children with special educational needs, in educational institutions and ensuring preparation of missing methodologies (recommendations) (Conclusion 3.4).
12. Organizing dissemination of information about methodologies (recommendations) that aim to help teachers organize quality education for children with special educational needs, by publishing methodologies (recommendations) on the website of the Ministry of Education and Science or other responsible institutions, and organizing specialist trainings related to these methodologies and others issues (Conclusion 3.4).
13. Assessing the need for special educational and academic measures required to organize quality education for children with disabilities and special educational needs, and providing educational institutions with these educational and academic measures (Conclusion 3.4).
14. In order to improve the organization of inclusive education and promote tolerant attitudes towards people with disabilities, providing in activity planning documents and implementing the measures related to increasing the society's tolerant attitudes towards people with disabilities in the field of education (Conclusion 4.1).

The plan for implementation of recommendations is presented in Annex 13.