



THE VELUX FOUNDATIONS
VILLUM FONDEN ✕ VELUX FONDEN



**COUNTRY REPORT –
ASSESSMENT REVIEW OF THE EARLY
CHILDHOOD INTERVENTION
SYSTEM IN HUNGARY**

**AUTHOR:
GÉZENGÚZ FOUNDATION**

JULY, 2018

Table of Contents

1. SUMMARY OF THE REPORT (250 SZÓ)	3
2. Introduction (1 oldal)	3
2.1. Information about the project, its goals and objectives	3
2.2. Goals and objectives of the country research	5
3. Methodology (3 oldal)	5
3.1. Desk study (<i>how the resources were identified, which resources were involved in the desk research</i>)	5
3.2. Qualitative research (<i>structural interviews</i>)	6
3.2.1. Brief description of the instruments/questionnaires used in the study	6
3.2.2. Procedure (<i>how the respondents were recruited, inclusion/exclusion criteria, how the participants were interviewed, ethical consideration, how the data has been analysed</i>)	6
3.2.3. Participants (<i>how many participants, brief background information about the participants</i>)	7
4. Results of the desk research (10 oldal)	8
4.1 Current situation with regard to the following domains	11
4.1.1. Screening, referral and the eligibility of the ECI system	11
4.1.2. Follow-up/monitoring	14
4.1.4. Interdisciplinary assessment	15
4.1.5. Evaluation of potential stress factors for families	16
4.1.7. Development and implementation of individualized service plan	16
4.1.8. Monitoring and evaluation of the results of the implementation of the plan	17
4.1.9. Transition to new settings	18
4.1.10. Policy, legislation and financial resources	19
4.1.11. Training of personnel	20
4.2. Conclusions and description of possible limitations of the study	22
5. Results of the structural interviews with service providers, families and when possible policy makers (max 10 pages)	22
5.1. Description of findings	22
5.1.1. Screening and referral	22
5.1.2. Eligibility for the ECI system	25
5.1.3. Follow-up/monitoring	25
5.1.4. Access point to the service system	27
5.1.5. Interdisciplinary assessment	27
5.1.6. Evaluation of potential stress factors for families	28
5.1.7. Development and implementation of individualized service plan	28
5.1.8. Monitoring and evaluation of the results of the implementation of the plan	30
5.1.9. Transition to new settings	30
5.1.10. Policy, legislation and financial resources	31
5.1.11. Training of personnel	32
5.2. Conclusions and description of possible limitations of the study	34
6. Discussion of the findings of both studies, general conclusion	34
7. Questions for future research	35
8. List of References - Bibliography	36
9. Appendix with relevant data, illustrations, photo's or statistics and tables, references to the relevant webpages, etc.	38

1. SUMMARY OF THE REPORT

The objective of the desk research carried out in the framework of the Agora project was to reveal the operational system of early childhood intervention, as well as to map the difficulties faced by the specialists working in the system and by families applying for services. The desk research basically examined eleven problem domains: (1) screening and referral, (2) eligibility for the system, (3) follow-up and monitoring, (4) access points to the service system, (5) interdisciplinary assessments, (6) evaluation of potential stress factors, (7) development and implementation of individualized service plan, (8) monitoring and evaluation of the results of the implementation of the plan, (9) organization of transition to new settings, (10) policy, legislation and financial resources, (11) training of personnel, qualification.

In order to receive a realistic view about the service system in the course of the research work we have interviewed fifteen specialists from different fields of early childhood intervention (healthcare, education, social sphere) providing early intervention. We have also interviewed families in order to get an impression not only about the current status of service provision, but also about the important „main actors” of early childhood intervention and about the difficulties and situation the families applying for services are facing. The feedbacks received were supplemented and we have compared them with the protocols and legislative regulations valid in Hungary.

2. Introduction

2.1. Information about the project, its goals and objectives

The AGORA project consists of an innovative pilot initiative developed in 5 Central and Eastern European (CEE) countries (Hungary, Slovakia, Poland, Romania and Bulgaria) addressed to overcome the challenges in the implementation of strategies to develop adequate Early Childhood Intervention (ECI) systems for children with disabilities at local and national levels. Therefore, the main goal of the project is to analyse the situation around ECI services in the 5 CEE countries. The objectives of the project are:

- to create an all-embracing learning and convening space to bring together essential actors to co-produce high quality ECI services
- to produce practical guidance and tools to provoke a systemic change on the social welfare system by improving the legal and policy frameworks at European, national and/or regional levels
- to develop examples that can serve as inspiring guidelines for other countries in Europe and other groups of children with special needs or at risk of exclusion (such as children with Roma or migrant background)
- to investigate the availability of ECI services for children with special needs in 5 CEE countries
- to collect and analyse available information and resources on the ECI services in the target countries reflecting the current situation
- to conduct a desk study and qualitative research exploring the existing ECI services in the following domains - screening and referral, eligibility for the ECI system, follow-up/monitoring, access point to the service system, interdisciplinary assessment, evaluation of potential stress factors for families, development and implementation of individualized service plan, monitoring and evaluation of the results of the implementation of the plan, transition to new settings, policy, legislation and financial resources, training of personnel
- to develop a database with the information about ECI service providers.

The ECI Agora project is supported by the Velux Foundation, were created by Villum Kann Rasmussen, whose mission it is to bring daylight, fresh air and a better environment into people's everyday lives. EASPD – European Association of Service providers for Persons with Disabilities - is also involved into the project. It is a wide European network, which represents around 15.000 services across Europe and across disabilities. The main objective of EASPD is to promote the equalisation of opportunities for people with disabilities (PwD) through effective and high quality service systems. EASPD has 20 years of experience in research and development of assessment tools, in European development of training and learning material and in management of European projects as coordinators as well as partners.

2.2. Goals and objectives of the country research

The purpose of the desk research is to present the current situation of early childhood intervention in Hungary. Our main goal was the analysis of the operation in practice of the service system, presentation of equalities and differences between the regions, or studying the practical implementation of theoretical guidelines and protocols. Furthermore, we aimed at the description of the current regulatory and financing, or development environment, since they basically determine the operation of the institutional system.

3. Methodology

3.1. Desk study

In the desk research we have basically taken into account the study on Regional status assessment to the foundation of network development of early childhood institutional system written and edited by Judit Kereki between 2010 and 2011, which was compiled in the framework of sub-project Development of early intervention network program of pillar No. 4 of „Services supporting the equal opportunities of children with special educational needs” based on the priority project support contract of EDUCATIO Társadalmi Szolgáltató Nonprofit Kft. (=Social Renewal Operational Programme) TÁMOP 3.1.1. Program Office, 21st century School Education – Development and Coordination. We have also used as a resource the study of Judit Kereki and Anna Szvatkó on Early childhood intervention, as well as special service protocol of counselling on special education, early development, education and nursing prepared in the framework of priority project TÁMOP-3.4.2.B-12-2012-0001 on the „Integration of children with special educational needs (Development of Special Services)”. The National Institute for Family and Social Policy (=Nemzeti Család- és Szociálpolitikai Intézet) – in the framework of TÁMOP-5.2.6-13/1-2014-0001 project – has collected international methods and good practices using social model approach and focusing on early detection in the field of early childhood intervention. The same is described in the study of Szilvia Cs. Ferenczi and Judit Csákvári on New approaches to the subject of early childhood intervention, which was also a help to us. Furthermore, technical articles and official websites have contributed to the country report as resources.

3.2. Qualitative research

3.2.1. Brief description of the instruments/questionnaires used in the study

The desk research raised two main questions, to which we wanted to get an answer:

- What ECI services are available for a child with special needs in the target countries?
- What is the structure and functioning of the ECI services according to the service providers, parents, policy makers?

To obtain comparable data questionnaires developed by Eurllyaid have been used as the main source of data collection. Structured interviews and the desk research are based on the questionnaires that are developed according to the different stages of the Systemic Developmental Model of M. Guralnick of the Early Intervention System (https://depts.washington.edu/chdd/guralnick/pdfs/overview_dev_systems.pdf).

We have totally used five tools in the desk research: (1) Questionnaire for the desk research, (2) Questionnaire for the service providers, (3) Questionnaire for the parents/families, (4) Letters accompanying the questionnaires, (5) Glossary. The questionnaires contained open questions and it took about 1-2 hours to answer them. The answers were given anonymously and the participants' data were treated confidentially.

3.2.2. Procedure

Desk research have been based on official reports and statistical data on the ECI services and legislation in the target countries and have been conducted by the project partners. Structured interview with service providers and families have been recruited and conducted by staff of Gezenguz Foundation. The participation was voluntary with the condition that the persons were ready to cooperate and to give a declaration of consent. The persons filling in the questionnaires – both the specialists and the parents – received oral and written information about the desk research, the latter was handed over personally, in printed form or was attached in electronic form, and their intention to assent was confirmed by their signing the declaration of consent.

3.2.3. Participants

Every country had to collect answers for the questions formulated in the questionnaire from at least 9 specialists working in the field of early childhood intervention. Three-three respondents had to be recruited from each sector, from healthcare, education and social matters in order to get the most complete picture about the current service system. The inclusion criteria was that every respondent had to have min. 1 year practical professional experience in the field of early childhood intervention, and all of them had to be familiar with the role of coordinating the organizations acting in the field of early development. As to the parents' questionnaires, all countries had to address min. 3 families/parents having a child with special needs. The only inclusion criteria was the experience of ECI services now or in the past in the target country.

In the framework of Agora project Gezenguz Foundation has contacted 15 service providers in the field of early childhood intervention, education, healthcare and social services in Hungary in order to collect information about the Hungarian practice. Of the fifteen respondents five are working in healthcare, five in public education and four in the social sphere and also a foundation working in the private sector helped us. In healthcare, the answers were given by pediatric neurologists, pediatrician head physicians in head of department position, and by a physical therapist, specialists working in the capital and in the countryside with 5-10 years practical experiences. In public education we interviewed special education service providers with several years of experience from a number of counties. The heads of the interviewed social institutions were also selected from different counties.

Of the families who were invited to fill in the parents' questionnaire always the mothers were the respondents. The mother of a 3 years old boy with sclerosis tuberosa diagnosis helped us. The child is delayed both in motoric and cognitive development. One of our respondent was the mother of an 8 years old girl, who was premature and when she was 10 days old she got a brain hemorrhage, resulted in spastic hemiparesis. Thus, the child is delayed in motor development and has visual problems. Our third respondent was the mother of an 8 years old boy also diagnosed with hemiparesis and of a 5,5 years of boy with coordination problems.

We have collected information about the regulatory and legislative background of the service system through participating in professional projects, using the up-to-date knowledge of legislative frames required to professional cooperation, from taking part in conferences and from official websites, articles and studies.

4. Results of the desk research

Early intervention is a service, to which according to (1) of Section 30 of Act LXXIX of 1993 on National Public education one has the right „from the time when the handicap is diagnosed”, that is from the time of being proclaimed as a person with special needs. The Act formulates that early intervention due in the framework of special care shall be provided on the basis of expert opinions of the competent specialists and rehabilitation committees /sub-section (2) of Section 30 of Act LXXIX of 1993 on National Public education. In our country the Act on national public education defines the right to early interventions and the obligation for providing services, while Decree No. 4/2010-es OKM regulates its organization. In this way early intervention composes part of public education as regards legislation, thus intervention is basically provided by the Pedagogical Services, which do not employ people with medical education. In addition to the educational actors the social and healthcare institutions are also institutional actors of the early childhood intervention system, or their representatives who get in contact with handicapped, disabled children, or with children with atypical or delayed development and behaviour and with their families (from the conception of the child up to his/her 5 (6) years of age/going to school).

It is evident for the specialist that the early intervention system requires the cooperation of several professions; the interdisciplinary approach and the cooperation between ministries supervising the different fields and the coordination of their work are of vital importance. The smooth implementation of this process, however is very difficult, since children and their families are typically dealt with in different areas of domestic provision (separately in educational, healthcare and social areas), thus there is a lack of communication between specialists working in different fields, and it also often happens that they do not know about each other's role and competence.

Several factors make difficult the determination of the number of children in need of early intervention: first, the target age group is not clearly defined, secondly, the involvement is also not clearly defined. In the closing report of the desk research led by Judit Kereki in 2009 on Operation of the institutional system of early intervention in Hungary the size of the population in need of early services was estimated by two different methods. Based on the available statistical data (KSH Census data, VRONY, data of PIC/NIC centers, results of former researches) and taking into account the proportions in international practice, about 10-15 thousand children in the 0-4 age group can be in need of early intervention in Hungary according to moderate estimates. On the other hand the district nurse database showed that there were 9030 children under the age of six in need of early intervention in 2009. According to the official data about the participants of early intervention (data of Expert Committees) approximately 2500 children received early intervention at home or at institutions in 2007. On the other hand, the results of the 2009 desk research showed that much more children received early intervention: according to rough estimation about 6000 children could get service in the early intervention institutions in 2007. **(Appendix 1.)** As a result of the research it was found that there were about 9-10 thousand children under the age of six in need of early intervention in 2007, of which about 5-6000 children received institutional service. This means that more children were provided service than indicated by the official statistics, while the proportion of children without service could be about 30 percent. (Kereki & Lannert, Operation of the Hungarian early intervention institutional system - Research closing report., 2009) In further desk researches no attempts were made for estimating the number of children in need of early childhood intervention. (Kereki, Regional status assessment to foundation of of nerwork development of early childhood institutional system - Research closing report., 2011)

Regarding the regional distribution of service provision, almost 50 percent of children have received intervention in Budapest in 2007. In several counties (Hajdú-Bihar, Nógrád, Somogy, Szabolcs-Szatmár, Heves, Borsod- Abaúj-Zemplén) the institutional intervention of children in proportions had lagged behind the level what the children in need of the given region would have required. The Northern Hungarian region had the biggest problems with service provision, where the

counties are below the national average in almost every indicator. **(Appendix 2.)**

Based on the data of about 100 institutions providing early intervention the number of children participating in early intervention is increasing year by year and had grown by about 20 percent between 2005 and 2007. **(Appendix 3.)**

The lack of specialists is a serious problem in many service fields. The proportion of vacant district nurse posts was 8,3% in 2015. (Central Statistical Office, 2016). The data of the National Basic Healthcare Institution as of March 1, 2016 showed that the proportion of vacant general practitioner posts providing family pediatric and mixed service is 8,3%. (National Basic Healthcare Institution, 2016). Nearly five thousand specialists are working in the institutions of the Pedagogical Special Services, while the personnel specified by the legislation is by 1300 persons more. (KIR-STAT, 2016) Regarding the proportion of specialists working in the early childhood intervention system the situation is the best in South-Transdanubia and in Middle Hungary, while the values are the worst in Central-Transdanubia and in Northern Great Plain. The table containing detailed data can be found in the Appendix. **(Appendix 4.)** The national distribution of therapists working in the system is shown based on 2008 data on the graphs attached in the appendix. **(Appendix 5.)** (Kereki & Lannert, Operation of the Hungarian early intervention institutional system - Research closing report., 2009)

In Hungary the diagnosis of the mentally, sensory and multiply impaired children started in the Special Educational Needs Psychological Institute of Bárczi Gusztáv College for Special Educational Needs Teachers, and during the decade that followed the system could successfully catch up with the early childhood support level provided by the Western countries through the experiences imported and as a result of the therapist and consultancy work started in Hungary. At the College, the practical activity started at the beginning of the 1980s with a program that aimed at the promoting of movement development of pre-kindergarten children, which was the basis of guided family education focusing on families. (Kereki, Regional status assessment to foundation of of network development of early childhood institutional system - Research closing report., 2011)

4.1 Current situation with regard to the following domains

4.1.1. Screening, referral and the eligibility of the ECI system

In our country a child can officially be included in the early intervention system based on the opinion of the so-called Expert and Rehabilitation Committee, by being proclaimed as a child „with special needs” with the complex diagnosis of the Expert and Rehabilitation Committee examining Learning Ability / Vision / Hearing / Motion / Speech. The Expert and Rehabilitation Committee examining Learning Ability is regionally available at several locations, while Expert and Rehabilitation Committee examining Vision / Hearing / Motion / Speech is only available in one place, in the capital city. At the age of 0–3 years the Expert Committee of the county shall determine the special educational need and shall make proposal for starting early intervention. Under the age of 18 months, however also the specialists of the Expert Committee issue an expert opinion based on the diagnosis of a pediatric neurologist, or other specialists (e.g.: neonatologist, orthopedic physician, etc.). This means that this age group is in a special situation as to the status cognition, since infants can get the necessary treatment without special examination based on the recommendation of a medical specialist. The medical examination should always be initiated by the parents, the doctor can only make a proposal for this after the neurological examination of the child. One can apply for the special examination in writing at the competent Expert Committee by filling in Annex 1 of Decree 15/2013 EMMI.

At the age of 0-3, in justified case (e.g. severely and multiply impaired) until the age of 5-6 years, the pedagogical special service institution in the school district closest to the home of the child is designated as place of service. The service contains complex special educational development, consultancy, improvement of social, communication and language skills, motion development and psychological support. The follow-up of the children by physical specialist and physiotherapy, however are not possible here. Therefore, the parents have to contact other institutions, where the neurological or other medical monitoring of the child, as well as his/her other physiotherapy and additional special therapy (feeding therapy, art therapy, etc.) can be provided. The provision of services in several institutions is an obstacle to coordinated work.

In case of children over 3 years of age/included into the kindergarten system the so-called Unified Special Needs Education Methodological Institutions are responsible for the comprehensive service provision. (Kereki, System of early childhood intervention – ways and connections., 2015)

In Hungary the screening of newly borns is regulated by Decree 51/1997. (XII. 18.) of the Minister of Welfare on (“Healthcare services and the certification of screening serving the Prevention and Early diagnosis of Diseases that are available in the framework of Compulsory Health Insurance”), or by its amendment in 2005 – Decree 67/2005. (XII.27.) of the Minister of Health – which regulates in detail the mandatory and voluntarily available age-related screenings. The Annex of the Decree lists the screenings to be made at the age of 0-6 years. Part of the work should be performed by the family pediatricians, the other part by the district nurses (regionally competent specialist, who is responsible for the follow-up of basic healthcare of children in the 0-18 age group). In the healthcare system, certain screenings are made already during pregnancy, and the child goes through different basic and additional screenings after birth, which in optimal case are carried out at the neonatal department at the age of 0–4 days. The following screenings are available with this support: complete physical examination, screening of developmental disorders, measuring of body mass, body length, head/chest circumference and their assessment according to the Hungarian standards, neurological test, detection of dislocated hip (with special knack, sometimes using ultrasound or X-ray), checking of sensory organs as to hearing and vision (red light, pupil reaction, visual behaviour), screening of inherited metabolic diseases. The prematures and the mature, but problematic newborns get to the neonatal/perinatal centers according to the protocol, where the appropriate screening examinations are also performed. After returning home the district nurse has an important role in screening, a screening system was developed in the framework of priority project TÁMOP 6.1.43, where on the one hand the district nurse is doing different tests, on the other hand the parents fill in a questionnaire based on their observations at 15 age periods (1, 2, 4, 6, 9, 12, 15, 18 months, 2, 2,5, 3, 4, 5, 6, 7 years), examining in this way the psycho-motoric development of 0–7 years old children. The screening covers the mapping of gross motor, fine motor,

hearing, visual, receptive, expressive language skills, social and emotional skills, behaviour and background abilities necessary to schooling, as well as the mapping of attention and adaptive thinking. Decree 49/2004. (V.21) on regional district nurse service specifically determines screenings to be performed by the district nurse. The family pediatrician and the general practitioner also perform screening in their scope of responsibility (musculoskeletal tests, screening of dislocated hip, examination of nervous system, examination of cryptorchism).

The specialists working in the educational consultant units can also perform tests – with the contribution of the parents – in order to prevent learning and integration difficulties among children, who take part in kindergarten education and are more than four years old. Furthermore, the basic survey of the speech and language development of children taking part in kindergarten education and being over five years of age is carried out in the framework of speech therapy service, and based on the result the further pedagogical, psychological and medical examination of the child can be initiated. (Decree 15/2013 (II. 26.) of Ministry of Human Capacities on the operation of pedagogical special services institutions, Section 24)

The parent cannot be obliged to avail of early intervention provided by the act on public education, and it is also up to the parent to take the child to the non-compulsory screenings and medical examinations, or to expert committee examinations under the age of 3 years. (Kereki, Regional status assessment to foundation of network development of early childhood institutional system - Research closing report., 2011)

The focal point of the service system is Budapest, where more than 50% of children in need of early childhood intervention are concentrated. Because of the wide range of available institutional services families are travelling to the capital even from far distances, if there is no appropriate institution in their vicinity, or since they do not have enough information, they do not know the closest possibilities. Unfortunately, specialized services are not available for residents of smaller settlements, especially in villages, since the institutions have mostly been organized in the big cities. Accessibility to services is limited by the physical distance, by the lack of financial resources and by the difficulties of travelling. Anyway, the complexity of the system make difficult not only the orientation, but also the access to services, there is no

typical, clearly regulated pathway. (Kereki & Lannert, Operation of the Hungarian early intervention institutional system - Research closing report., 2009) In order to promote accessibility the Child Aid project started in 2008 based on EU funds. The Sure Start program based on inter-sectorial cooperation and operated together with civil organizations aims at granting equal opportunities for 0–6 years old children through local initiatives. The program's main objective is to provide complex support to families bringing up small children in disadvantaged regions, villages, urban residential areas and housing estates through the prevention of healthcare, social and adverse mental consequences of child poverty, as well as providing equal service and care to small children according to the need of their age. (Herczogh, 2008)

4.1.2. Follow-up/monitoring

After the inclusion in the system follow-up is of outstanding importance. The premature infants, newborns small for their gestational age, and all mature newborn who were in need of intensive care for any reasons after birth require follow-up, even if the neonatologist who sent them home, or the family pediatrician do not find any problem, or if no problem is detected by the district nurse during screening. In the first three years control tests should be made with the „problem-free” children minimum 1-2 times per year. Follow-up is necessary until the schooling age, but the way, the carrying out and frequency of follow-up are not regulated by the procedure. In the course of follow-up the separation of internal medical and development neurological tasks is important, as well as the family pediatrician should be informed and involved into the aftercare. If due to lack of specialists, the neurological follow-up of the child cannot be solved, it is necessary to involve physicians with child rehabilitation specialization. (Vekerdy & Mramuracz, 2006) Psychologist, or special education teacher, or movement therapist should be involved into the aftercare.

At the end of the intervention year the specialists of the Pedagogical Special Services evaluate the development of children in early intervention. If after the regular care the child's condition has improved and no further treatment is necessary, the child can be released from the system with issuing a summary assessment sheet. If in case of the child under the age of 18 months the country and district special committees

issued the expert opinion without examination, only based on the diagnosis and therapy recommendation of the specialist physician, the review examination should be made at the end of the first school year after the starting of early intervention and care. From the first official review examination until the child's receiving early intervention and care the expert opinion shall be re-examined every second school year. In case of children between the age of 18 months and 3 years officially initiated re-examination is performed by 1 year after the basic test. After this, if the child is a little mentally retarded, or has other psychological disorder, the expert opinion shall be officially reviewed every second year until the school year when he/she reaches 10 years of age; after that and in case of other disabilities, and also when having autism spectrum disorder, or if the client has integration, learning or behavioural difficulties the official review should be made every third school year until the age of 16 of the student. (Kereki, System of early childhood intervention – ways and connections., 2015)

4.1.3. Access point to the service system

In Hungary the access point to the early intervention service system is the Expert and Rehabilitation Committee of the competent region, or in special case the Visual, Hearing, Speech and Motion Examining Expert Committees with national scope of authority.

4.1.4. Interdisciplinary assessment

Since 2009 several specialists have worked in a number of projects and pilot projects as a result of which the below detailed theoretical background has been developed to the foundation of reform efforts and to process regulation currently under preparation in Hungary.

Early childhood intervention service can only be provided with holistic-based approach. Accordingly, during the screening test and the referral process the infants and toddlers are viewed by the system not in themselves, but in their bio-psycho-social relations and a language is spoken that is understood by the representatives of the different sectors and can be used by them in their work. (Kereki, System of early childhood intervention – ways and connections., 2015) During the past decades the family-centered approach and the importance of family environment have received greater focus in the early childhood intervention. The capacities, abilities, resource

organization and self-representation of the family became very important. Consequently, the family is involved in every areas of early intervention: the status confirmation itself is carried out on the request of the parents and the parent receives preliminary information about the methods of the examination, what can only be carried out with his/her consent, and the parents can be present during the examinations; the comments and remarks of the parents are taken into account in the condition survey; the parent is also a member of the interdisciplinary team, who is the cooperative partner of the specialists on different levels of the planned and developed services, although his/her involvement is limited; the composition of the interdisciplinary team is in line with the needs of the child and the family. (Kereki & Szvatkó , Early childhood intervention, as well as special service protocol of special needs educational consultancy of early development, education and care., 2015)

4.1.5. Evaluation of potential stress factors for families

In order to assess the stress factors of families and their resources the specialists are making participating and revealing observations in the shared social spaces of the social, child protection and child welfare institutions. If a problem is detected the specialists of child welfare service can convene a case conference with the participation of the concerned specialists. In the framework of the healthcare system the specialists collect detailed information about the circumstances and status of the family during the examination (both about the social and psychological conditions). If serious stress factors occur during the dialogue, they contact the family (pediatrician) physician, the district nurse, and if necessary the child welfare organizations (child welfare and family support service).

4.1.7. Development and implementation of individualized service plan

Based on difficulties revealed during the examination an expert opinion is prepared, in which the number of sessions needed to development is determined based on the act on public education. If possible, early intervention is held with weekly regularity in the number of hours specified by the Expert Committee, based on individualized development plan in close cooperation with the families. At the closing of the specialist examination consultation will be held, where the parents are informed about the results, about the findings, diagnosis, development proposals, the possible

content of the expert opinion and if necessary, proposals can be made for additional examinations. In the outpatient service the parents also participate in the sessions, this is however not possible if the intervention take place in a nursery. Here the regular consultations with the parents and caretaker of small children ensure the collective thinking. The parents may accept in writing the result of specialist examination, and may also refuse it. The specialists prepare family service providing plan with the involvement of the family members. The service providing plan contains the description of the baseline situation, the targets, tasks and services, which will help the child/family during the process. Decree 4/2010 describes in detail the necessity of documentation about the development of the child by the service providing institution and about the control role of the Expert Committees. (Kereki & Szvatkó , Early childhood intervention, as well as special service protocol of special needs educational consultancy of early development, education and care., 2015)

4.1.8. Monitoring and evaluation of the results of the implementation of the plan

In the Pedagogical Special Services the specialist providing early intervention prepares one year development plan based on the expert opinion, a copy of which shall be sent to the expert and rehabilitation committee and the development is provided on this basis. The committee reviews the service providing plan and if necessary makes proposal for its modification. The specialist is keeping an individual development record on a centrally designed document and evaluates the results also on a centrally formulated form (assessment sheet) at the end of the school year. The assessment sheet shall be filled in three copies of which one will remain at the developing institute, and one-one copy will be sent to the parents and to the Expert Committee. Based on the findings of the assessment sheet, or on the examination and re-examination of the child the Expert and Rehabilitation Committee may modify – if necessary – the impositions of the expert opinion concerning early intervention and the organization of provision of care. On the initiation of the parents or of the institute taking part in early intervention and care the Expert and Rehabilitation Committee – maximum once a year – shall re-examine the child. If the child is placed in a nursing home for handicapped children the committee shall perform the re-examination of the child ex officio, and also if it regards it necessary

based on the individual service providing plan and the assessment sheet. As a result of the revision the committee will modify the expert opinion as applicable, or the fact of revision will be confirmed in a report. The Expert and Rehabilitation Committee proposes that the maintainer exercise professional control over the institution of early intervention and care, if this is deemed necessary based on the assessment sheet and the re-examination. (Kereki & Szvatkó , Early childhood intervention, as well as special service protocol of special needs educational consultancy of early development, education and care., 2015)

4.1.9. Transition to new settings

Pursuant to Decree 15/1998. (IV. 30.) of Minister of Welfare a child can be enrolled in a day-nursery from his/her age of twenty weeks until three years of age, in case of handicapped children until five years of age, or till December 31 of the year, when the child becomes three years old, or the disabled child will be five years old. The disabled child can be enrolled for habilitation purposes and taken care of in the day-nursery suitable for early intervention, if this kind of recommendation is given by the Expert and Rehabilitation Committee in the expert opinion, and if the child does not endanger the body integrity of himself/herself and his/her mates during the nursery care. When the child becomes five years old the Expert Committee shall make a statement about the abilities of the child in an expert opinion in order to decide, whether the child can participate in kindergarten education or development care is recommended. If the child changes institution, the sending institute shall forward the expert opinion, the individual service providing plan and the assessment sheet to the receiving institution. (Kereki & Szvatkó , Early childhood intervention, as well as special service protocol of special needs educational consultancy of early development, education and care., 2015) Children with disability can be enrolled in day-nursery for probation period, the shortest time of which is one month. After the probation period decision shall be made about the further taking care of the child in view of the collective opinion of the specialist team directly dealing with the child (physician, special needs teacher, nurse). In the day-nursery the disabled children can be included in a mixed group with healthy children or in special nursery group. The number of children to be cared for by one nurse should be determined depending on the condition of the children included in the special group, but their

number cannot exceed three children per one nurse. In a day-nursery group maximum 12, in a group also caring for disabled children maximum 10, and in a group only caring for disabled children maximum 6 children can be tended. (Kereki, Regional status assessment to foundation of of network development of early childhood institutional system - Research closing report., 2011)

4.1.10. Policy, legislation and financial resources

Providing early intervention to impaired children and children with different development is regulated by ministerial fundamental laws and by executive orders, by the Act on National Public education adopted in 1993 and by Decree 4/2010 of the Ministry of National Economy and Development, by social act of 1993 and by Decree 1/2000. SZCSM, by Act on child protection of 1997, by Decree 15/1998 NM and by Act on mandatory social insurance of 1997 – and by a number of other Ministerial and governmental decrees. Their connection is partly ensured by Decree 4/2010 of the Minister of Education and Culture, which contains common regulations concerning the institutional system of early intervention. The regulation of healthcare, however is almost totally independent from the interrelated system of the other two sectors. Detailed rules of early intervention are contained in Decree 15/2013 (II. 26.) of the Ministry of Human Capacities. (Kereki, Regional status assessment to foundation of of network development of early childhood institutional system - Research closing report., 2011)

The financing of early childhood intervention institutions is very varied. On the one hand the difference appears on sectorial level, since the funding of the social and educational institutions is different from the financing of healthcare institutions in the framework of healthcare insurance. On the other hand, there is a difference as to the maintainer, since the financing of institutions supported by municipalities (settlement and county financed institutions) and that of multi-purpose small regional institutions is significantly different from the non-municipal and non-multi-purpose small regional institutions. Money arrives at the institutions from three sources, partly from the state budget, partly from the maintainer, and partly from other sources connected to the institutional level (e.g. donations, parents' contributions). The currently valid financing frameworks are determined by Act CXXX of 2009 on the 2010 central budget of Hungary. State financing of early intervention

and care is basically implemented through the normative budget support of municipalities who are responsible for fulfilling the tasks. The budget act contains the annual specific amount of early intervention and care (today 240 THUF/person), as well as the criteria of claiming. Money arrives from the central budget to the institutions of early childhood intervention basically through three channels: from the budget of competent ministries through normative contributions due to the municipalities and small regional associations, through the intervention-based healthcare insurance contributions arriving directly to the institutions from National Health Insurance Fund of Hungary, and through the different tender opportunities. The first channel is available to institutions under the control of education and social ministry, the second is available to the healthcare institutions. The tender invitations generally aim at equipment investments or specialized trainings in the field of early childhood intervention. (Kereki, Regional status assessment to foundation of of network development of early childhood institutional system - Research closing report., 2011)

4.1.11. Training of personnel

The domestic institutional system of early childhood intervention comprises all healthcare, public education, social, child protection, child welfare and other institutions, and their representatives, who get in contact with children requiring special support and with their families from conception till the child's going to school. For this reason in the field of medical care the institutional actors are the obstetrician, the neonatologist, perinatal/neonatal intensive centers, baby and/or newborn departments of hospitals, the child rehabilitation specialists, family pediatricians, nurses, pediatric neurologists, institutions of early rehabilitation/habilitation, pediatric psychiatrists, clinical psychologist, geneticist, ophthalmologist, ENT physician, audiologist, orthopedic physician and other specialized physicians, dietitian and physiotherapist; in the field of social care the child welfare services, family and child care services in countryside, family supporting centers, homes for children, day-nurseries, family day care homes, family child care, regional child protection service and child guardianship agency, social workers, family supporters, baby and toddler caretaker; while in the field of public educations the institutions of Pedagogical Special Services (school district, county,

national), kindergartens, Expert Committees, Uniform Special Needs Education and Conductive Pedagogical Methodological Institute, kindergarten pedagogue, special education teacher, psycho-pedagogue, somato-pedagogue, conductor. Other institutions include private service providers and the interest protecting organizations of disabled persons. The system of early intervention requires the cooperation of several sectors and professions. The interdisciplinary approach and the cooperation and coordination between ministries supervising the different areas are of vital importance. The smooth running of this process, however is problematic everywhere in Europe. Even if several actors are dealing with the child and his/her family in the domestic system, typically there is no communication between the service providing specialists and it often happens that they have no information about each other's role. Today, the control over the professional work performed in the system is exercised by inspectors (in different structure and intensity per sectors), who check in their traditional scope of responsibility, if the services are provided according to the standards and whether the actors operate on good professional level. In practice, the professional work is coordinated by the team leaders in the member institutions, while on institutional level by the working community leaders and the high level work is ensured under their supervision. In Hungary early intervention is basically, officially provided by the Pedagogical Special Services on normative basis, the professional control belongs to the school district leaders and to the heads of County Pedagogical Special Services.

Today, there is no professional control in Hungary, which monitors the quality of early intervention activities in the broader sense.

In our country there is a wide spectrum in the qualification of the specialists working in the field of early childhood intervention. In Hungary the requirement concerning the qualification is that the medical specialist should have valid and regular permit for operation and a registration number. Based on former researches it can be said that the biggest number of employees with secondary school education (matriculation) working in early intervention are employed by the day-nurseries and by caring homes for disabled persons being under the control of the social ministry. Specialists with university degree can be found in the greatest number in the healthcare institutions or in the early intervention centers. The most highly educated

workforce is employed by the multi-functionally integrated institutions operated by foundations. In our country, many accredited post-graduate trainings are available for specialists of early intervention. These training courses are licenced by the Ministry of Human Capacities and are accredited by the Educational Office. Pursuant to Decree 63/2011. (XI. 29.) of the Minister of National resources – on rules of continuing education of health workers – persons performing healthcare activities shall mandatorily take part in medical professional trainings. In the field of public education, the pedagogues should take part in at least 120 classroom sessions every 7 years. (Kereki & Lannert, Operation of the Hungarian early intervention institutional system - Research closing report., 2009)

4.2. Conclusions and description of possible limitations of the study

We had difficulties with the desk research, because such terms as early development, early intervention and early habilitation are not clearly defined. The target age-group is also not determined precisely enough. Our work was also made difficult by the fact that children and their families are dealt with on several levels in the domestic system – separately by educational, healthcare and social areas – all of them using their own regulations and the activity and communication aiming at a common objective cannot be seen. Other impeding factor was the lack of databases, missing of descriptive and comparative statistical data, due to which it is difficult to get a comprehensive view about the whole institutional system. Another problem is the different method of operation, as a result of which the institutions have statistical data about children for different periods due to their belonging to different ministries. All these factors were a limitation of the study.

5. Results of the structural interviews with service providers, families and when possible policy makers

5.1. Description of findings

5.1.1. Screening and referral

From the field of education our respondents were heads of Pedagogical Special Services from several counties. Based on the answers received we have a very varied picture about the operation of the Pedagogical Special Services. There are institutions where there is no screening at all, while in others decision is made about

the necessity of further examinations based on a screening type condition assessment led by the special needs teacher. These screenings include the detail taking of anamnesis, parents administered questionnaires about the current status of the child, conductive operative monitoring, as well as taking SEED Development Scale or Bayley III screening test. In view of the answers received we may say that in most cases the parents voluntarily – personally or in e-mail or by phone – contact the Pedagogical Special Services based on the indication or recommendation of the district nurses and family physicians/ pediatrician. Referral is not needed to registering for early intervention, but it happens in some cases that the family arrives with referral issued by the family pediatrician, or specialist. Decree 15/2013. (II.26.) of the Ministry of Human Capacities regulates the operation and system of care of the Pedagogical Special Services, thus entering into the official system of early childhood intervention of Pedagogical Special Services is only possible based on an expert opinion, there are, however institutions that also accept the families for the request of the parents or for the doctor's recommendation (and provide services for the children not on the account of 'early intervention') and ask the opinion of the Expert Committee only "in case of necessity" (probability of longer and intensive intervention).

Most of our respondents from the medical sphere were pediatricians, pediatric neurologists (in head of department position) and a physiotherapist was also at our help, who is the head of an early intervention institute in the countryside. Based on the feedbacks received we may say that the neurological examination of the child is carried out on the recommendation of the family doctor or on the request of the parents (private services) under the guidance of a pediatric neurologist specialized in development neurology and in some places with the help of physiotherapist/special education teacher/clinical psychologist/electro-physiologist, electrotherapeutic assistant/ nurses with keeping the limits of the competence and according to the protocol of development neurology. In order to exclude organic damage the specialists may refer the child to a detailed development neurological examination, if necessary to the Development Neurology Department of Szt. Margit Hospital or to other institutions for children (e.g. MRE Bethesda Children Hospital, Pediatrics Clinics of Semmelweis University). The results of the examinations and if necessary the

proposed treatments will always be discussed with the parents and family members. In general, we may say that the specialists follow the clinical medical guideline valid since 13.11.2017 „Professional Guideline of the Ministry of Human Capacities about development neurology and neuropathy”, published in No. 18 of 2017 of Medical Bulletin.

In our desk research, we have found that no screenings are made by the foundations carrying out early intervention, neither by the developing centers interviewed by us. Most of the families arrive at these institutions on the recommendation of the physician with referral, although this is not a precondition of using the service - “we accept in some form all children who are referred to us” – and the families may apply for the service on their own, too. Nevertheless, if a family wants to avail of the therapy financed by the foundation/developing centre, the child should have a proposal for therapeutic care from a pediatric neurologist/Pedagogical Special Service.

We cannot speak about actual screening in case of institutions working in the social field, either. The specialists can assess the development of children arriving here during their daily life activities and in the framework of the different club activities (e.g. movement, singing/telling rhymes, creative sessions). In certain cases (e.g. certain children homes) besides the nurses and special needs teachers taking care of infants and toddlers sometimes a pediatrician, district nurse and psychologist also assess the child’s condition. If any problem is detected by the specialist, the medical check-up of the children begins. The concerned children are examined by the Pedagogical Special Services’ team after which a special opinion is issued based on which the early intervention can be started. In children homes early intervention is provided by the associates of the Educational Consultancy Service in the period and in the way specified by the expert opinion, but the service provision is also assisted by specialists with pedagogical education and working in the home. If there is a specialist with special needs teacher/conductor qualification and the Expert Committee finds the social institute proper for caring for the child, the committee may designate the said social institute for providing early intervention to the child.

Since there is no clearly regulated pathway for the patients, the families contact with their problem the medical and public education institutions at the same time, since

they do not know where to turn. The institutions of medical care demand referral from the general practitioner or from a specialist, the issue of this document is free of charge, while this is not needed when applying for care at the Pedagogical Special Services. According to the parents' feedback detailed diagnostic tests were made with the children in both places.

5.1.2. Eligibility for the ECI system

It was a general feedback from the social field that the specialists working in this area do not have the competence to decide about the eligibility of the children for early childhood intervention, they can only formulate recommendations for the family.

As to public education – if the family belongs to the scope of sub-section (2a) of Section 4 of Decree 15/2013. (II. 26.) of the Ministry of Human Capacities – eligibility is determined by the member institution of the school district, thus the educational institutions have the authority to determine eligibility.

In the healthcare sphere this issue is more complex: of the medical staff of the institution only the specialist physicians have the right to determine eligibility. „But after reaching the 18 months of age they can only make proposal to the parents for early childhood intervention, in this case examination of the expert committee is needed to the use of the system, what the parents/tutelars should initiate in writing at the competent county or national Pedagogical Special Services, or in special cases at the Sight, Hearing, Movement and Speech Testing Special Committee with national scope of authority.”

5.1.3. Follow-up/monitoring

In the healthcare institutions follow-up of children in need of early intervention is always ensured. The control tests are scheduled by the specialists at the age of 1, 2, 4, 6, 9, 12 months and if necessary at 15, 18 months of age with 3month, half year or one year intervals depending on the problem. In severe cases, control tests can be made every week or every fortnight. In problem free cases the finishing of care is scheduled by the time when the child starts walking independently. Based on preventive approach children whose development inhibiting risk factors are high (e.g. prematures, newborns with small weight, children with difficult family or

perinatal anamnesis) are always monitored in the healthcare system, whether the child is eligible for early intervention, or not. If there is no significant development delay in infant and toddler age and the child is not included in the early childhood intervention system, the child is referred to the district nurse and family care network, or before going to kindergarten specialist examination is proposed in order to decide about eligibility for future kindergarten development (special needs education, speech therapy, movement therapy).

In the practice of public education, continuous follow-up takes the form of educational guidance for children who are granted the status of children with Integration, Learning and Behavioural problems (and are already not children with special educational needs). If based on the expert opinion of the control test made at the age of 3 or before starting kindergarten further development is not justified, practically there is no official follow-up, it depends on the personal contacts, if the families give feedback about the development of their lives and of the child. If further development is necessary, the child will be proclaimed as one with special educational needs (SNI) the Expert Committee will make control tests with a frequency specified by the law, but this is not identical with monitoring or care. Monitoring and care are always provided according to the family's needs and in view of the institute's capacities, in coordination with the parents, thus in every case with taking into account the character of the problem and the criteria of the specialist, if necessary with repeating the complex examination.

In the social sphere there is no actual follow-up e.g. in case of children leaving the children homes. Nevertheless, in case of families/mothers doing regular visits the psychosocial and biological changes of the children and the family are continuously monitored in the framework of partner care.

The families do not always know the competences of the other fields, they are not aware of in which cases and with what conditions they can apply for support. It was mentioned as a problem that the necessary specialists could not always be provided to the developments prescribed by the special services.

5.1.4. Access point to the service system

In Hungary the access point to the early intervention service system is the regionally competent Expert Committee, or in special cases the Visual/Hearing/Speech/Motion Examining Expert Committees with national scope of authority. In most cases the access point to the different institutions is telephone contact, website and e-mail. The families have no information about an office where they can turn to for official information about support.

5.1.5. Interdisciplinary assessment

In the framework of public education interdisciplinary assessments are in general carried out with the help of special needs teachers and conductors – if necessary with the involvement of psychologists – based on complex bio, psycho and social approach. Here Bayley III or SEED Development Scales, conductive operative and special need education, or psychological monitoring systems are used. Parents get information about the possible tests and the methods used already during the first interview. Parents are also active participants of the assessments, they are mostly present during the assessment and help the work of the specialists with their comments. If necessary the specialists send the families to expert committees in order to determine/exclude the special educational need status.

In the healthcare sphere the assessment survey is mostly made in the framework of pediatric neurological test, the protocol valid in Hungary is the Medical Professional Guideline on „Development neurology and neuro-therapy „of the Professional College of the Deputy State Secretariat for Healthcare of the Ministry of Human Capacities. The specialists take detailed anamnesis, and then they assess the child’s actual status using the tools of pediatric neurological tests. The test is made under the guidance of a pediatric neurologist, who can be assisted by physiotherapist, special needs teacher, clinical special psychologists, electro-physiologist assistant, electro-therapeutic assistant and infant nurse. Parents are informed about the results and about each step of the examination and of making conclusions.

Interdisciplinary assessments are less typical in the social field, the routines are different depending on the institutions. Development sessions for children included on the basis of specialist’s counselling generally begin with a longer observation

phase, where the special needs teacher try to assess the abilities, skills of the concerned children during different sessions, taking into account the reports of the parents and the expert opinions. In certain associations psychologist, pediatrician, district nurse and mental hygienic specialist lead individual and small team counselling with pre-determined frequency, or if so required at custom dates.

The feedback of parents show that the families are in practice mostly informed about the results of assessment test only later, they have no preliminary information or explanation about the assessment methods. In every case the parents were present during the assessments, what were made by one or more specialists depending on the character of the examination.

5.1.6. Evaluation of potential stress factors for families

Since in the social field the assessment is not a well-tried practice, there is no special system for the screening of potential stress factors. In the course of the different sessions the specialists get information about the families arriving at the social institutions, they get an insight into the family resources and stress factors.

The specialists are mapping the potential stress factors, the family supporting networks and the family resources in the course of discussing the life histories (language, speech and movement development history, medical and biological anamnesis, function development, socio-economic status, emotional-social and cognitive development, important life events, home and institutional tuition, interventional attempts so far, familiar data) in the framework of tests made by the Expert Committees in the education sphere, and through pediatric neurological examination in the healthcare system. Furthermore, consultation between the pediatrician/district nurse and parents allows for the survey of the family resources and stress factors. The interviewed families also reported that during the assessment surveys they were thoroughly questioned by the specialists about the current situation, resources and concerns of the family.

5.1.7. Development and implementation of individualized service plan

In Hungary early intervention basically belongs to the education system, thus the official service providing plan also belongs to the responsibility of this sector. Based on the difficulties found by the specialist investigations an expert opinion is

prepared, where the necessary number of regular weekly sessions is determined. Early intervention shall be carried out on the basis of this individualized service providing plan, which is defined by Decree 15/2013. (II. 26.) of the Ministry of Human Capacities on the operation of the institutions of Pedagogical Special Services. At the end of the examination a consultation is held where the parents are informed about the results, findings, the diagnosis, proposals for development and the possible content of the expert opinion. The parents may accept in writing the results of the tests or may refuse it. In theory the early intervention specialists of all the three fields should follow the service providing plan defined by the Expert Committee, but their scope of authority covers only the pedagogical sphere.

In general „check-up and treatment” plan, or recommendation is also prepared by the healthcare institutions: primarily the pediatric neurologist takes part in this process, but his work is assisted by a team consisting of a physiotherapist, clinical psychologist/teacher of special needs education, electro-physiological assistant, electro-therapy assistant and infant nurse.

So-called individual care-education plan is prepared in the social institutions, which contains the most important factors, tasks, responsible persons and deadlines relating to the child. The plan is compiled by the staff of the home at the time of inclusion of the child and is updated about every half year.

In the questionnaire the parents gave the following answers to the question about the service providing plan - „After the inclusion of the child into some kind of early intervention did you get information about the services you can avail of? Is there any regulatory obligation for such plan in your country?” – the parents gave the following answers: “I have no information about such plan and regulatory obligation.”, “I do not know about regulatory obligation. The recommended therapies were determined after the check-ups.” The proposed therapies were rather used in the form of private service, against payment. According to the feedbacks the neurologist and the specialists responsible for development continuously monitor the children’s development, the necessary developments and their frequency are determined on this basis in agreement with the parents. Since development sessions are provided not within one institution, on the whole the parents are mainly coordinating the process.

5.1.8. Monitoring and evaluation of the results of the implementation of the plan

The monitoring of the official service providing plan is the following: “If as a result of expert examination the child gets into the early intervention system, he/she will be re-examined by the Expert Committee at the age of 18 months, 3 years, or every one, two or three years until 16 years of age. The validity of the expert opinion is limited in time and this is indicated in the expert opinion. Within this interval extraordinary revision can only be initiated with due reason.” Besides this specialists working in the healthcare system also monitor the diagnosed children, they recall them every 3 or 6 months for control, but in more serious cases this interval can be shorter.

5.1.9. Transition to new settings

“The county and/or national Expert Committees (in case of sensory organ and motion disabled child) can make recommendation for transition of the child from early intervention to kindergarten.” According to the current legal regulations the district educational institution has to accept small children with special educational needs, if the foundation document of the institution contains the integration of population belonging to the given disability group. If the parents do not want to enroll the child in the locally competent kindergarten, a declaration for inclusion is required from the selected institution. In certain cases the continued impairment-specific education, development, habilitation and rehabilitation of the children is carried out in segregated kindergarten groups. The time of getting into kindergarten is selected by the specialists working in early intervention and by the parents taking into account the development pace of the child. But to be included in the new special service is a long process, thus in practice rather the capacities of the developing educational institution and the family needs determine to what extent the specialists take part in the process.

The medical institutions take a lesser part in this process, if necessary they give a comprehensive description about the child’s condition, about institutional development, the initial condition and the results achieved in order to make the work of the new institution easier. We have learnt from the parents’ feedback that in practice they organize themselves the transition into a new special service, they

are looking for the possibilities and the institutions. The parents usually go to the Expert Committee, eligible for designating the institution already with the declaration for inclusion, which contains the statement of the kindergarten or the school that they can solve and undertake the integration and development of the child.

5.1.10. Policy, legislation and financial resources

In Hungary early intervention is basically provided by the regional and county Pedagogical Special Services whose work is regulated by Act CXC of 2011 on National public education and by Decree 15/2013. (II. 26.) of the Ministry of Human Capacities. Services provided by the Pedagogical Special Services, thus the early childhood intervention services are free of charge. The educational institutions are financed from the central state budget: the institution prepares its own budget based on the central budget, the maintainer finances the operation, the resources are not separated for the special tasks. Financing of specialists is continuous, but the purchase of new assets is strongly limited. In addition to this there is possibility for applying for EU sources on governmental level. The healthcare institutions are operating taking into account the healthcare legislations, the patients' rights and the children's rights. In detail: Act CLIV of 1997 on Healthcare, Decree 26/2014. (IV.8.) of the Minister of Human Capacities on Care for pregnancy, Act CXC of 2011 on National Public education, Act III of 1993. on Social administration and social benefits, Act XXXI of 1997 on the Protection of children and the Administration of Guardianship, Act XXVI of 1998 on the Rights and equal opportunities of persons with disabilities, Act CXXV of 2003 on Equal treatment and the promotion of equal opportunities, Act LXIV of 1991 on the Publication of the New York Convention of November 20, 1989 on the Rights of the Child, Decree 15/2013. (II.26.) of Ministry of Human Capacities on the Operation of the Pedagogical Special Services' institutions, Act LXXIX of 1992 on the Protection of fetal life, Decree 60/2003. (X. 20.) ESzCsM on Professional minimum standards necessary to healthcare provision, Decree 49/2004. (V. 21.) ESzCsM on Regional district nurse service, Guideline to basic care of children to providing screening services to children of 0-7 years of age. National Medical Officer's Office, Budapest 2014. Public health institutions operate under OEP

funding, with service obligation on the whole territory of the country, and they provide services without social insurance against payment determined by the law. Decree 9/2012. (II. 28.) NEFMI contains the Definition of outpatient specialist services financed by the Health Insurance Fund the conditions and rules for accounting as well as performance based settling of accounts ("Outpatient specialist service Book of Rules"). In case of private healthcare practices/ institutions developments are financed by the families. Financing of institutions working in the social field show a similar picture. In the public institutions services are provided free of charge, while in case of institutions operated by NGOs services are provided for fee. Some institutions manage themselves from tender and own sources.

Based on the answers received from the parents we may say that the early intervention of a child costs about 10-15 000 HUF per week. This includes a number of different motion therapies/physio-therapy, manual treatment, hydrotherapy/swimming one-two times per week. In the state-financed Pedagogical Special Services system mainly pedagogical consultancy and special needs educational development can be used. In many cases this is also utilized through private channels, in which case the amount increases proportionately. The government supports the families with higher family allowance, which means an additional 10,000 HUF per month.

5.1.11. Training of personnel

Decree 15/2013. (II. 26.) of the Ministry of Human Capacities on the Operation of the institutions of Pedagogical Special Services contains that early intervention and care can be provided in pedagogue jobs by special needs teachers, psychologist (clinical pediatric specialist psychologist, clinical and mental hygienic (adult) specialist psychologist, counselling specialist psychologist, neuro-psychological specialist psychologist) and conductors. The educational and teaching professional work can be directly assisted by a physiotherapist that is not in a status corresponding to his/her qualification. Specialists taking part in fieldwork can expand their knowledge by taking part in postgraduate trainings and in accredited training courses. It is mandatory for pedagogues to take part in min. 120 school sessions every seven years. These trainings, however are supported by the state to a lesser extent

financially, the member institutions “make efforts for supporting the specialists with their possible scarce financial sources (e.g.: ensuring time for one training day per every half year)”. Occasionally, there are opportunities for taking part in governmental trainings organized from EU sources, but the specialists are mostly taking part in trainings at their own cost and in their free time according to their needs. „Internal trainings”, however are quite frequent, where the elder, more experienced colleagues share their knowledge with the newly graduated specialists. In a given member institution the team leaders, while on institutional level the working community leaders coordinate the professional work and development and contribute to high level work. On institutional level, the general director is responsible for the managing and control of the professional work, and he/she is doing his/her job through the member institution directors and the professional working communities. The keeping of legislative rules and the documentation of the work is checked on site annually by the institution’s management (general director and general director deputies). The professional control of the special field is carried out regularly on local level according to the Organizational and Operational Rules of the institution based on detailed rules of internal control under the direct supervision of the member institution director and deputy member institution directors (special needs education teachers) entrusted with the direct managing and control of the special task, if necessary with the involvement of the person coordinating the working group. Decree 15/2013. (II. 26.) of the Ministry of Human Capacities on the Operation of institutions of Pedagogical Special Services contains, that the activities of early intervention and care can be performed in non-pedagogue positions by specialist physicians or child and youth psychiatrists, infant care and pediatrics, or pediatric neurological specialists, physiotherapist, pedagogical assistant and assistant of special needs education taking into account the type of disability. The specialists taking part in examination and therapy have valid and regular operational registration. Pursuant to Decree 63/2011. (XI. 29.) of the Minister of National resources – on rules of further training of health workers – persons carrying out healthcare activity are obliged to take part in professional trainings. According to this Decree, the healthcare worker has to receive theoretical

training corresponding to his/her qualification during the training period in order to meet the training requirements.

In the social sphere mainly special needs teachers, tutors and psychologists are employed full-time, while the district nurse, the pediatrician and the physiotherapist are working with work assignment contract. Certainly, specialists working in the social field also have the opportunity to take part in trainings, but there is no requirement towards them as to the training.

5.2. Conclusions and description of possible limitations of the study

In spite of the efforts made until now the three spheres of early intervention are still working according to separate schedules and there are only a few connection points. Separate development plans are prepared in the different fields and services are provided parallel and in many cases the parent is the mediator between the service providers. The Expert Committee making decision about the official, state-financed early intervention has no competence regarding the actors of the healthcare and social spheres. In many cases the state financed service system with a nationally organized network cannot fulfill its tasks due to lack of specialists and resources. Thus, the parents have to spend much more money on obtaining services for their children than the amount granted by the state as a support to the families (family allowance).

6. Discussion of the findings of both studies, general conclusion

Our aim with the desk research was to map the operation of the service system and to get a realistic view about the practical implementation of the valid theoretical protocols, about the difficulties that the specialists working in the system have to face and about the obstacles the families face during the patient paths, children paths. As a conclusion of the desk research we can state that there is no typical, clearly regulated referral process, patient path, what makes difficult not only the situation of the families, but also the work of the specialists. In order to ensure the efficient operation of the early intervention system it is by all means necessary to ensure the cooperation and team work of the different professions and special fields, but this is a great challenge, since the regulation, financing, specialist training

and operation of the three fields – public education, healthcare and social – show very different picture.

The EFOP-1.9.5-VEKOP-16 Inter-sectorial development of early childhood intervention project under the professional guidance of Judit Kereki, economist and special needs teacher started in 2016 as part of the reform process launched in 2009, which, however mainly focuses on the kindergarten age-group.

Screening and monitoring are established for all children until 7 years of age in healthcare. If any delayment is detected the family is sent to the neurologists or directly to private service providers without deeply assessment. There is another client way especially for children after 3 years of age – who get in preschool institutes – they are sent to Expert and Rehabilitation Committee through which get in officially ECI system (without being assessed by healthcare professionals) and they get free services. Assessments are done parallely in the different sectors with minimal communication between the professionals. The preventive intervention is not involved in the official ECI system, not supported by the government, it is provided by private services. Only children proclaimed as „children with special needs” are involved in the official ECI system provided by Pedagogical Special Services from zero but there aren't enough well-educated professionals who can work with children under 3. Furthermore there are big differences in proximity and accessibility in the different areas of the country.

7. Questions for future research

How can the performance of tasks of the nationally developed system of Hungary (Pedagogical Special Services) be enlarged and matched in multidisciplinary way with the family needs, how can we help and improve its work with the involvement of other highly qualified specialists dealing with early intervention (e.g. healthcare specialists and private practices).

It would be a step forward to work out the quality management protocol of services for the better quality of life of families and for the efficient healing of children, for improving their condition and their equal opportunities (social integration).

8. List of References - Bibliography

- Cs. Ferenczi, S., & Csákvári, J. (2015). New approaches to the subject of early childhood intervention. *Esély: social and socio-political monthly* (5).
- Herczogh, M. (2008). A koragyermekkorai fejlesztésre, programokra vonatkozó nemzetközi kutatásokról. *Védőnő*, 13 (4), 3-10.
- Kereki, J. (2017). Development targets and directions in early childhood intervention. ELTE Bárczi Gusztáv Special Needs Education Faculty, General Special Needs Educational Institute and Atypical Behaviour and Cognition Special Needs Educational Institute. *Gyógypedagógiai Szemle*, 45 (2).
- Kereki, J. (2011). *Regional status assessment to foundation of of network development of early childhood institutional system - Research closing report*. The study was prepared in the framework of sub-project Development of early intervention network program of pillar No. 4 of „Services supporting the equal opportunities of children with special educational needs” based on the priority project support contract of EDUCATIO Társadalmi Szolgáltató Nonprofit Kft. (Social Renewal Operational Programme) TÁMOP 3.1.1. Program Office, 21st century School Education – Development and Coordination.
- Kereki, J. (2015). System of early childhood intervention – ways and connections. State Health Service Center, ELTE Bárczi Gusztáv Special Needs Education Faculty, General Special Needs Educational Institute and Atypical Behaviour and Cognition Special Needs Educational Institute. *Gyermeknevelés*, 3 (2), 55-76.
- Kereki, J., & Lannert, J. (2009). *Operation of the Hungarian early intervention institutional system - Research closing report*. The study was prepared on the order of the Department of Disability matters and Rehabilitation of Ministry for Social Affairs and Labour, on the order of Equal Opportunities of Persons with Disabilities public Non-profit foundation based on Contract no. K-4206/08.
- Kereki, J., & Szvatkó, A. (2015). *Early childhood intervention, as well as special service protocol of special needs educational consultancy of early development, education and care*. Prepared in the framework of TÁMOP-3.4.2.B-12-2012-0001 priority project on „Integration of children with special educational needs

(Development of Special services)". Educatio Társadalmi Szolgáltató Nonprofit Kft., Budapest.

Vekerdy, Z., & Mramurác, É. (2006). *Elemző tanulmány a "Közös kincsünk a gyermek" Nemzeti Gyermek egészségügyi Program VIII. céljához. "Régióként komplex gyermek-rehabilitációs ellátás kialakítása, feltételeinek megteremtése".* . Országos Gyermek egészségügyi Intézet - Országos Orvosi Rehabilitációs Intézet.

9. Appendix with relevant data, illustrations, photo's or statistics and tables, references to the relevant webpages, etc.

Appendix 1.

Estimation of number and proportion of persons receiving early intervention (based on institutional database, 2007)

Database	Developers from the original list	Average serviced persons based on database	Envisaged total number of persons	%
nurse, carer at home	14	5,1	71,1	1,13
children's home	5	8,9	44,5	0,70
nursery, kindergarten, day care center	37	10,4	384,2	6,09
early rehabilitation	4	170,5	682,0	10,80
early intervention	6	235,5	1413,0	22,38
special service, special committee	31	29,0	897,5	14,22
psychiatry	22	102,0	2244,0	35,55
other healthcare, social foundation, other	14	8,1	113,6	1,80
TOTAL	149	42,3	6313,9	100,01
Corrected with cumulation (based on the birth database children are on the average taken into 1,4 institutions, but in reality this can be much lower, since more educated people were over-represented in the desk research)			4510,0	

Note: The database does not contain Margit Hospital with 500 children and the Institute of Anna Dévény also with 500 children.

Source: Kereki, J., & Lannert, J. (2009). *Operation of the Hungarian early intervention institutional system - Research closing report*. Institutional database, TÁRKI-TUDOK - FSZK

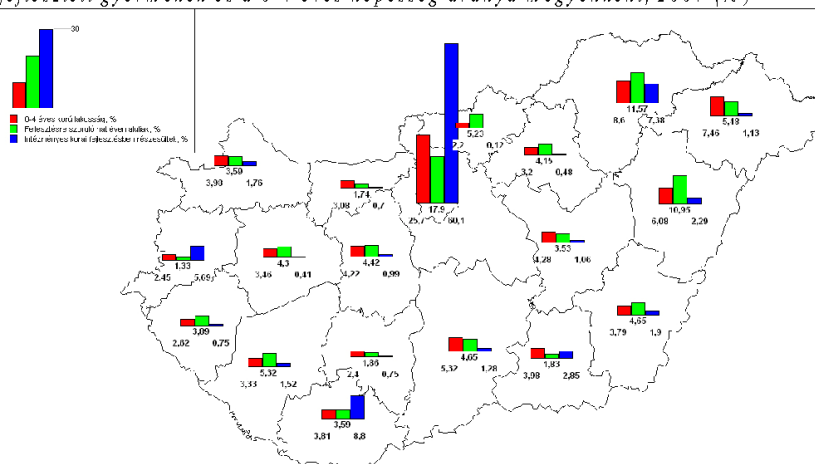
Appendix 2.

Map

Number of children under six years of age in need of early development according to district nurses, children developed in early development institutions and proportions of 0-4 years old population per counties, 2007 (%)

Térkép

A védőnők szerint fejlesztésre szoruló hat éven aluliak, a korai fejlesztő intézményekben fejlesztett gyermekek és a 0-4 éves népesség aránya megyénként, 2007 (%)



Source: Kereki, J., & Lannert, J. (2009). *Operation of the Hungarian early intervention institutional system - Research closing report*. Census data, KSH, institution and District Nurse database, TÁRKI-TUDOK, FSZK

Appendix 3.

Number of children provided institutional early intervention based on data of 100 institution

Year	Total	Average number	Spreading
2005	3441	35,11	83,04
2006	3808	38,86	98,46
2007	4147	42,32	108,7
Jan-Aug, 2008	3730	38,06	105,6

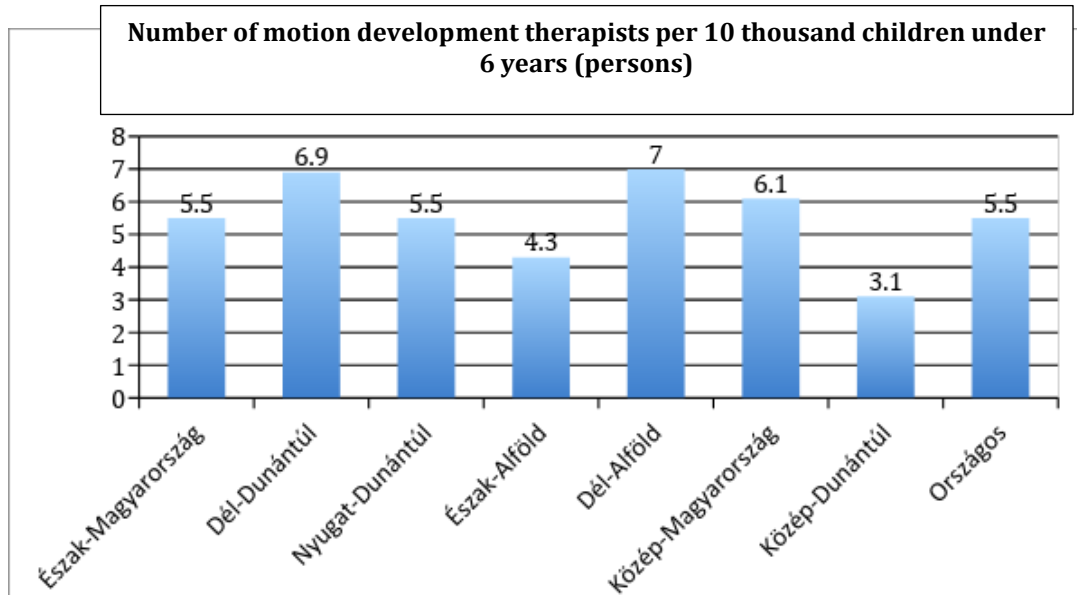
Source: Kereki, J., & Lannert, J. (2009). *Operation of the Hungarian early intervention institutional system - Research closing report.*

Appendix 4. -

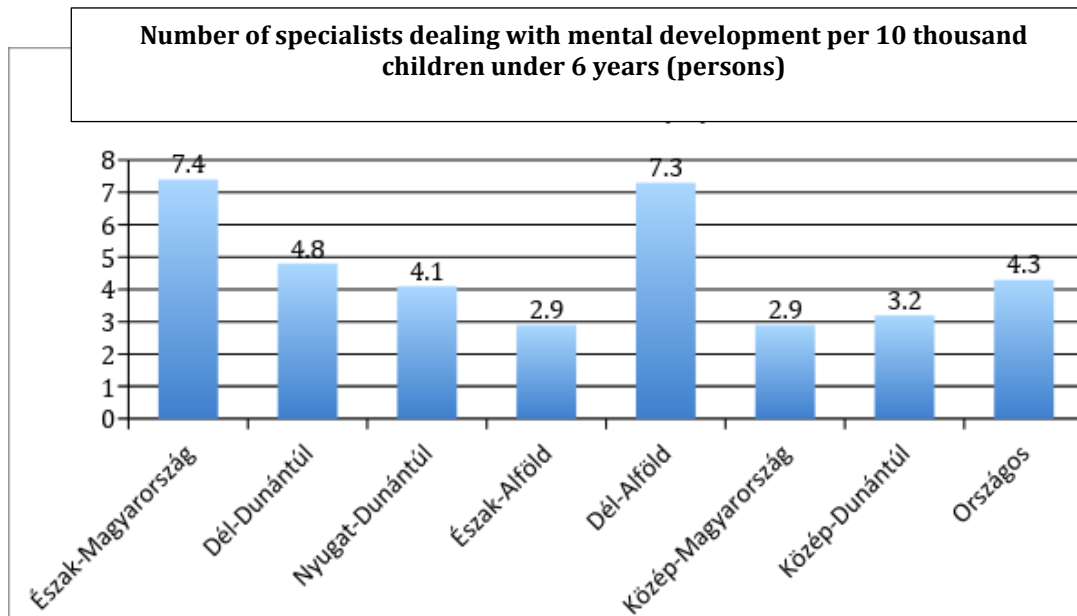
	Proportion of obstetrician-gynecologist per 100 thousand inhabitants	Number of 0-4 years old per one family pediatrician	Number of 0-4 years old per one pediatrician neurologist	Number of 0-4 years old per one pediatrician psychiatrist	Number of 0-4 years old per one district nurse
Middle Hungary	16,5	278	3048	2286	168
Middle Transdanubia	9,6	314	7364	5155	131
Western Transdanubia	12,8	328	4057	6376	114
South Transdanubia	16,7	297	6195	3336	106
Northern Hungary	12	371	10030	6687	111
Northern Great Plain	10,7	367	7778	4321	128
South Great Plain	13,7	280	5429	2844	116
National	13,6	310	4835	3405	130

Source: Kereki, J. (2011). *Regional status assessment to foundation of of network development of early childhood institutional system - Research closing report.*

Appendix 5. – Source: Kereki, J. (2011). *Regional status assessment to foundation of of network development of early childhood institutional system - Research closing report.*

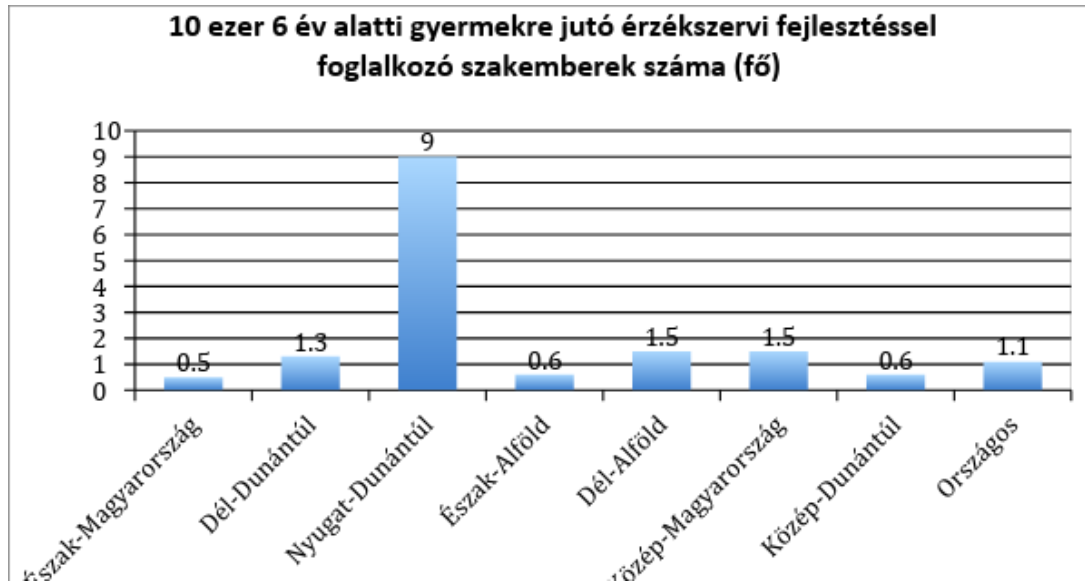


North Hungary South Transdanubia Western Transdanubia Northern Great Plain South Great Plain Middle Hungary Middle Transdanubia National



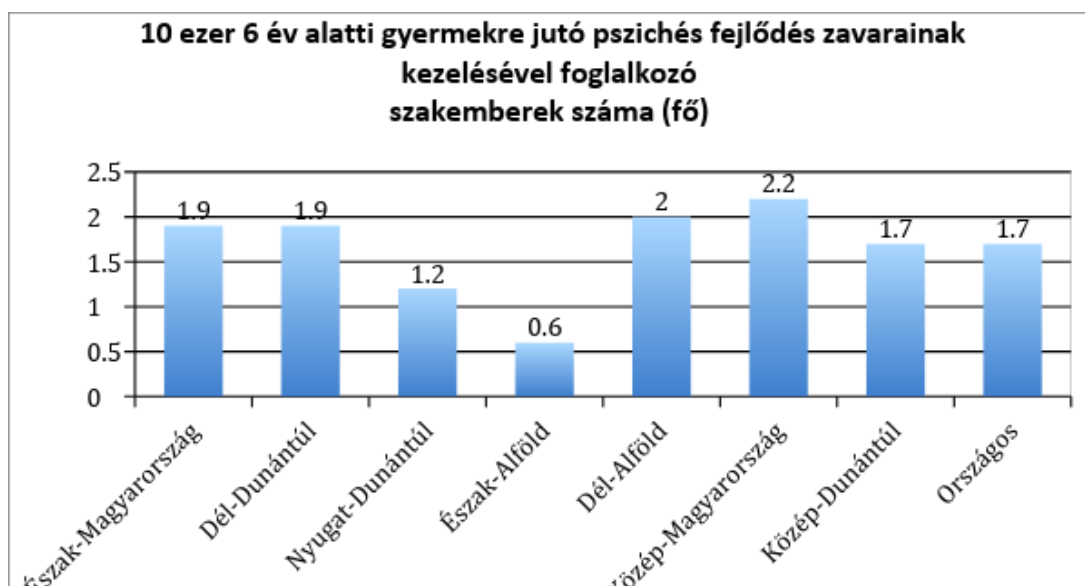
North Hungary South Transdanubia Western Transdanubia Northern Great Plain South Great Plain Middle Hungary Middle Transdanubia National

Number of specialists dealing with sensory development per 10 thousand children under 6 years (persons)



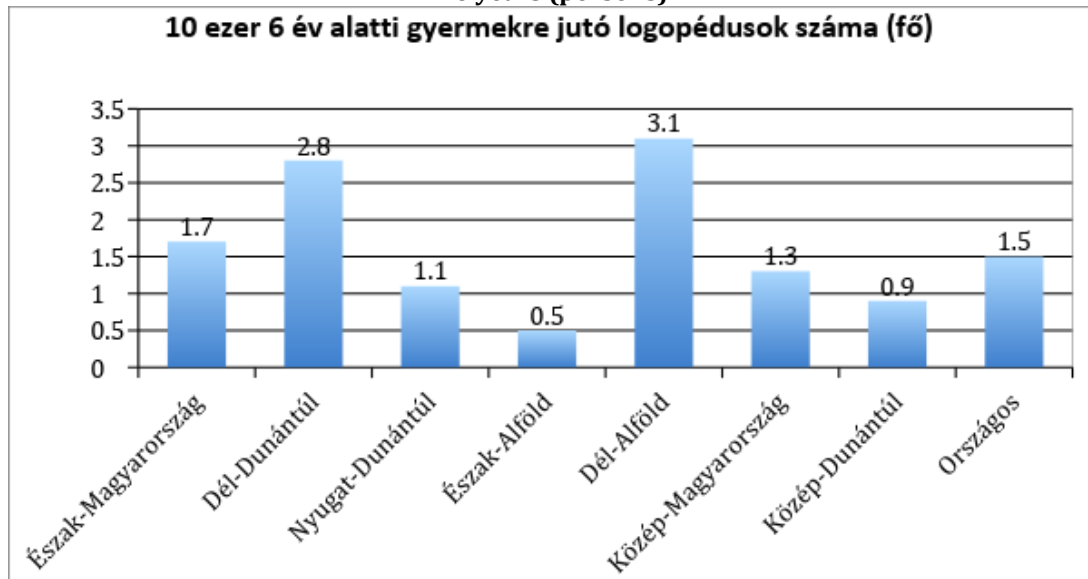
North Hungary South Transdanubia Western Transdanubia Northern Great Plain South Great Plain Middle Hungary Middle Transdanubia National

Number of specialists dealing with the treatment of psychological disorders per 10 thousand children under 6 years (persons)



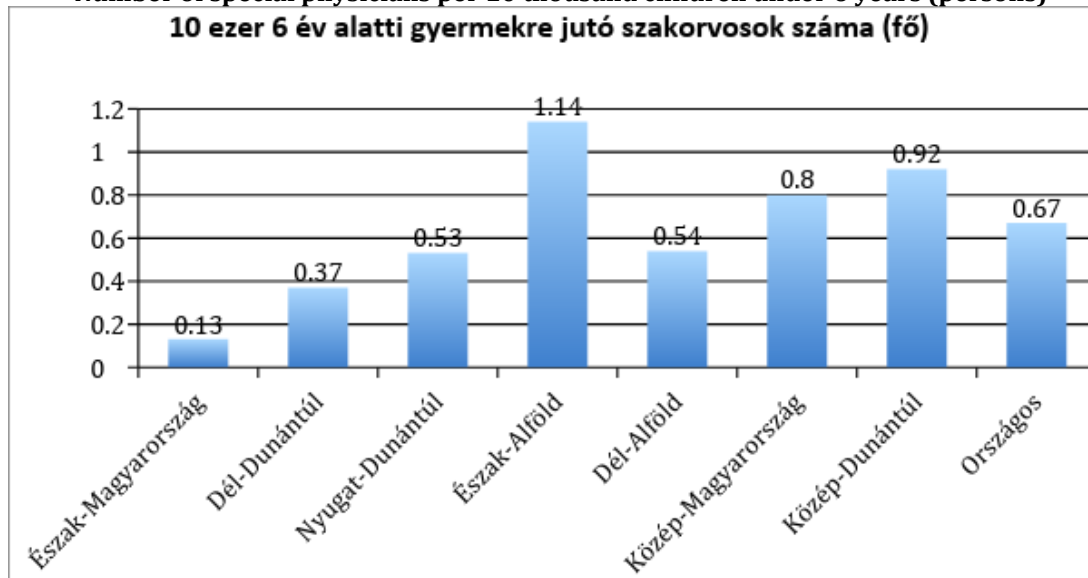
North Hungary South Transdanubia Western Transdanubia Northern Great Plain South Great Plain Middle Hungary Middle Transdanubia National

Number of speech therapists per 10 thousand children under 6 years (persons)



North Hungary South Transdanubia Western Transdanubia Northern Great Plain South Great Plain Middle Hungary
Middle Transdanubia National

Number of special physicians per 10 thousand children under 6 years (persons)



North Hungary South Transdanubia Western Transdanubia Northern Great Plain South Great Plain Middle Hungary
Middle Transdanubia National