

## Vocational Training for Physiotherapists about Family Centered and Play Based Approaches in Early Childhood Intervention (ECVET Based) Project

2017-1-TR01-KA202-046189

# Country Status Report about Early Childhood Intervention Systems in Partner Countries (Turkey, UK, Portugal)

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## Review of EU Policies

2019

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## 1. Introduction

This report was prepared by project partners for each partner countries to show how the early intervention system is working and what the mechanism are in these countries.

## 2. Early Childhood Intervention System in Turkey

### 2.1 The population of baby at risk and experts in Turkey

#### 2.1.1 What is the population of 0-3 year age babies, and baby at risk under 3 years of age?

The population of Turkey is 80 810 525 people as of December 31, 2017. The population of under 18 age years old is 22 million 883 thousand and the population of under 3 years old is 3 million 933 thousand. 1 million 291 thousand babies was born at Turkey in 2017. Turkey has 7 geographical regions. There are big differences between regions in the population of children. Child population is 46.7% in the South-eastern Anatolia Region. Child population in Trakya region is 19% [1]. Maternal education rate and pre-school education rate are also lower in South-eastern Anatolia.

The prevalence of premature birth is 12% in Turkey. We can say 157,000 babies are born early each year. There are 465,000 premature babies under the age of three. The prevalence of cerebral palsy is 4.4 per 1000 live births. This rate is twice that of European countries. There are 15450 babies with cerebral palsy under 3 ages.

The primary school graduate is 100% at 2018. But the rate of primary school graduation is 85-95% for women between 20-40 years of age. Maternal education level is very important for child development[2]. There are 200.000 to 600.000 baby with low maternal education.

The prevalence of developmental delay (motor, speech, social) among children aged 3–60 months is 6.4%. Significant associations were found between developmental delay and maternal age, maternal/paternal education, socioeconomic level of the family and the presence of consanguineous marriage. [3]. According to this rate the population babies with developmental delay is 251700.

#### 2.1.2 What is the population of school age children with motor, cognitive, speech and social problem?

The prevalences of developmental disorders were given by Turkish Statistical Institute; hearing impairment (6%), visual impairment (1.4%), speech, language impairment (4.4%), attention deficit and hyperactivities (1.4%), behavioural problems (1.5%), cerebral palsy, cognitive disorder, autism (2%) [4].

Total 373.942 pupils are supported at Special Education and Rehabilitation Center and inclusive education [5, 6].

#### 2.1.3 What is the proportion of the expert dealing with baby at risk?

22000 physiotherapist, special education teacher, child development expert, psychological counselor are working at 2074 Special Education and Rehabilitation Center [7].

There is 1 physiotherapist for 88 preterm babies.

There is 1 physiotherapist for 1 cerebral palsy.

There is 1 physiotherapist for 13 developmental delays at school children.

1. Kurumu, T.I. *Istatistiklerle çocuk*. 2018; Available from: <http://www.tuik.gov.tr/PreHaberBultenleri.do?id=27596>.
2. ŞAHİN, E. and H.Ç. ÖZTEKE, *1980-2000 YILLARI ARASI HÜKÜMET PROGRAMLARINDA İLKÖĞRETİM*.
3. Demirci, A. and M. Kartal, *The prevalence of developmental delay among children aged 3-60 months in Izmir, Turkey*. Child Care Health Dev, 2016. **42**(2): p. 213-9.
4. Kurumu, T.I. *Istatistiklerle Çocuk*. 2014; Available from: [http://www.tuik.gov.tr/IcerikGetir.do?istab\\_id=269](http://www.tuik.gov.tr/IcerikGetir.do?istab_id=269).
5. Bülteni, İ., *Temmuz 2017*.
6. T.C. Milli Eğitim Bakanlığı, S.G.B. *Milli Eğitim İstatistikleri Örgün Eğitim 2016/2017 Yılı*. 2017; Available from: [http://sgb.meb.gov.tr/www/icerik\\_goruntule.php?KNO=270](http://sgb.meb.gov.tr/www/icerik_goruntule.php?KNO=270).
7. *Fizyoterapist Sayısı ve Fizik Tedavi Bölümü Kontejanları*. 2016.

## 2.2 The Early Intervention Process in Turkey

### 2.2.1 How a baby join early intervention system?

There is no systematic model for early intervention and also there is no state program called 'early intervention'. There is systematic program supported financially by state for rehabilitation. Every individual who wants to benefit from the rights given to the disabled person by the laws has to prove the disability. The legal document defined by the law is the Disability Report which is given by Health Boards.

This report can be obtained from public hospitals affiliated to the Ministry of Health of the Republic of Turkey, from hospitals which are authorized to give the disability report as health boards. Those with a disability rate of over 20% may apply to Guidance Research Centers affiliated to the Ministry of National Education and issue a Special Education and Evaluation Board Report.

Individuals can receive services from the Special Education and Rehabilitation Centers affiliated to the Ministry of National Education by using the report.

In these centers;

Physiotherapy

Special education

Speech and language therapy

Psychological support services are available

All the babies who have this disabled board report can receive 8 sessions for a month freely at Special Education and Rehabilitation Center.

### 2.2.2 Is early intervention mandatory for babies at risk?

No it is not mandatory. If the doctor who follows the baby thinks that the baby is at risk; he/she tell the parents his/her suggestions. It is up to the parents to follow the suggestions and go to any rehabilitation program.

### 2.2.3 Is there eligibility criteria for participating in an early intervention program? What is the criteria?

There is a guidebook named 'High Risk Baby Follow Up Guide' published in 2014 by Ministry of Health. In this guidebook there is categories for babies at risk; mild, moderate, severe. It is written that babies at severe risk must be followed by a neurologic expert. It is also written that for the babies who:

- can't hold head at 3 months
- can't roll at 6 months
- can't sit at 8 months
- can't still walk at 18 months

Must be examined for diseases that cause neuromotor development delay.

But this guidebook makes only suggestions and in real life it is generally up to the doctors opinion. If the doctor makes guidance for rehabilitation and parents accept they can join to a rehabilitation program. They can take the sessions paying by themselves or they can receive 8 sessions in a month free if they have the disability report. The disability board report is given in only authorized hospitals with a board including pediatric neurology, child psychiatry and physical medicine and rehabilitation specialist. Disability Health Board Report determines rates for developmental problem. If the disability rate is above the twenty percent, it will be accepted to the Special Education Evaluation Board. Parents make an appointment with the health board report from the guidance research center. Assessment is made with objective, standardized tests and measurement tools appropriate to the characteristics of the individual by Special Education Evaluation Board in guidance research center. With this evaluation, an educational diagnosis is made. Assessments are include; mental, physical, psychological, social development characteristics and competences in academic disciplines, educational performance, areas of need. The duration of benefiting from training services and the Individual Development Report are also considered. Apart from the members of the Special Education Evaluation Board, when necessary; a person to be selected from other professions such as education programmer, audiologist, psychologist, social worker, speech and speech therapist, physiotherapist and specialist physician, representative of the relevant institution for the vocational training center and widespread education may participate as a member of the board.

During the educational evaluation and diagnosis process, the individual's overall developmental characteristics, educational qualifications, and academic discipline needs are identified for educational purposes. As a result, a decision is made to guide at least the restricted educational

environment. The guidance research center determines educational modules and specialization areas according to disabled medical board report and own assessment.

Babies receive 8 sessions of therapy a month after completing the disabled medical board report and guidance research center training module. Therapies apply center-based which called Special Education and Rehabilitation Center.

Special Education and Rehabilitation Center have to have special education teacher, physiotherapist, psychological counseling and guidance, child development specialist experts. If the parents need psychological support, they can receive free therapy in Special Education and Rehabilitation Center.

#### 2.2.4 How to decide which discipline will support the babies and their families?

Because motor development delay is more obvious at first months doctors generally refer the baby to physiotherapist first. Physiotherapist makes her/his own assessment and refer for other services according to baby's needs. But there is no systematic follow up program.

#### 2.2.5 Which institute support financially early intervention program and until when?

Every individual (no matter how old he is ) who wants to receive free rehabilitation service must have the disability report. Ministry of National Education and Ministry of Health support the rehabilitation services as long as you have this disability report. If the baby or child has no diagnose and no disability report than the parents must pay the fee for any kind of therapy.

Children with disability diagnose ( for example CP, spina bifida) can also receive physical therapy services up to 90 sessions per year under the Social Security Institution (SSI). The fees are paid by SSI. If the child had a surgery or botox, he/she can get additional 30 session for physical therapy and rehabilitation with a report obtained from a hospital. They can get this service from:

- Hospitals
- Medical Centres
- Physiotherapy Branch Centre

There are both state and private medical centres/ institutions and rehabilitation clinics/centres (State and Private University Hospital, State and Private Hospital, Private Medical Centre, Private Education and Rehabilitation Service, Private Physiotherapy Branch Centre).

#### 2.2.6 Which experts work in the early intervention system and what are the roles?

As we mentioned we don't have early intervention system in Turkey.

In rehabilitation centers there have to be psychologist, physiotherapist, special education teacher.

In hospitals with neonatal intensive care unit (NICU) there are newborn nurses. Newborn nurses are responsible for all the care of the babies in the incubator. Newborn nurses do the positioning, feeding exercises and provide maternal care and breastfeeding training before discharge. But again there is no systematic program for that.

Very generally, physiotherapist is the first contact person after the referral of a doctor. Physiotherapist can refer to other professionals in case of need, but it is very personal, there is no systematic way for that.

## 2.3 Early intervention as a policy in Turkey

### 2.3.1 When and how did early intervention support start in your country?

In the last 30 years, modern technology has developed and helped to keep more babies alive with the development of neonatology. Therefore, the number of infants have developmental risk factors such as prenatal, natal and postnatal, especially premature birth, has increased.

These developments revealed the early intervention needs of infants and their families.

Early intervention and developmental follow-up practices have developed in the early two thousand years. Initially, early intervention system started in 1992 within the Pediatric Neurology Department of Child Health and Diseases of Istanbul University Faculty of Medicine. In this model, Physiotherapist, Child Development Specialist, Neurologist worked together. Infants who were hospitalized due to prematurity or other risks in the newborn unit were first directed to the physiotherapy and rehabilitation center after being routinely examined in the newborn polyclinic and then in the pediatric neurology clinic. At the physiotherapy center, babies visited once a month until they reached the age of two. Approximately 50 babies were followed per month. Those with developmental risk from these babies were directed to the child development and education specialist, while the families were directed to psychological counseling according to their needs. When necessary, they were directed to genetic / metabolic units etc. The early intervention studies in this hospital continued until July of 2011. This model, which is thought to be practical for our country in that time, could only be applied in one center.

In recent years, awareness is increasing in the field of early intervention in our country. Some university and state hospitals, private centers and a non-governmental organization (TSÇV) have early intervention units. But these centers are located in metropolitan cities.

Gazi University, Hacettepe University in Ankara, Marmara University, Zeynep Kamil Hospital and TSÇV in İstanbul, and Dokuz Eylül University in İzmir has Early Intervention Unit. Also some private centers have early intervention teams.

The rights of the children in the constitution are as follows

According to Turkey Republic constitution the measures taken for children and the disabled persons can not be contrary to the principle of equality.

On behalf of the Republic of Turkey signed in New York on March 30, 2007 "Convention on the Rights of Persons with Disabilities" was found appropriate to approve.

Legislation of social services provided to CP children (daily care centers and services for children with CP, etc.)

According to Article 6 of the Law on Disability;

Psychosocial support and nursing services are provided in accordance with their situation so that disabled people can live independently in the environment they are living in. In the presentation of support and care services, the biological, physical, psychological, social, cultural and spiritual needs of a person are taken into account in consideration of the family. The work necessary for the standardization, development and dissemination of support and maintenance services is carried out by the Ministry of Family and Social Policy.

- Legislation which regulates access to medical care, services, rehabilitation and ongoing treatment

According to Article 10-11 of the Law on Disability;

Habilitation and Rehabilitation,

Article 10

Habilitation and rehabilitation services are given to disabled people on the basis of social life participation and equality. The active and effective participation of the disabled and his / her family is ensured at every stage including the taking, planning, execution and termination of the habilitation and rehabilitation decision.

It is essential that the habilitation and rehabilitation services be started as early as possible and the obstacle should be provided in the closest place to the settlement. Training programs are developed to train the personnel needed for the rehabilitation and rehabilitation services. Necessary measures are taken to ensure accessibility to assistive technologies and assistive devices used in habilitation and rehabilitation.

According to the law about the disabled persons:

Early diagnose and preventive services

Article 11- follow up of the newborn, early childhood and every period of childhoods physical, auditory, sensory, social, spiritual and mental development, ensuring early detection of diseases that may be genetic and cause disability, prevention of disability, withdrawal of the severity of existing disability to the lowest possible level and studies for stopping progress are planned and carried out by the Ministry of Health.

Basic law on health services: Medical and educational studies are carried out before and during pregnancy to prevent the birth of disabled children. Measures are taken to determine the risk carriers of newborn infants through tests required for metabolic diseases. The law against hereditary diseases: The state struggles in the context of preventive health services with hereditary blood diseases, including thalassemia and sickle cell anemia, with all hereditary blood diseases and other hereditary diseases leading to disability. The appropriation for this is set in the Ministry of Health annual budget.

Legal support for the parents and financial support:

The child must have the report about his/her diagnose from the Ministry of Health in order to benefit from all legal ( e.g early retirement, free permission) and financial support.

For mothers with disabled children are entitled to 12 months of part-time work on condition that 12 months have not passed since birth. This part-time work is full salary. Every mother who has disabled

child can benefit from this law, without caring the severity of the child or income rate of the family. Also part-time work (half of salary and personal benefits) can be demanded until the child's elementary school time.

Parents who have disabled child working in public institutions are exempted from duties and overtime.

All Turkish citizens and blue card holders receive birth allowance of 300 TL for the first born child, 400 TL for the second child and 600 TL for the third and subsequent children.

There are NGOs for special conditions like Down Syndrome Association, Spinal Muscular Atrophy Association, different associations for premature babies. These NGOs generally work for increasing the awareness about the diseases and find financial support for needy babies or children.

### 2.3.2 Is there any structured early intervention program in your country?

There is no common model for early intervention in our country. The portage early education program, the small steps early education program, the interaction based early childhood intervention program (ETEÇOM), and neurodevelopmental therapy (Bobath) methods are implemented in different centers.

### 2.3.3 What are the procedural responsibilities of early intervention practitioners? (Reporting and registration)

Diagnosed children evaluation motor, social, cognitive evaluation and individual training plan are prepared when they are first started to therapy in special education and rehabilitation center. Monthly progress of the baby is recorded during the intervention. When the report is renewed, all documents are sent to the relevant guidance research center. These documents are taken into account in the guidance research center for preparing new educational modules.

In special centers, assessment and therapy application is at the discretion of the relevant expert.

### 2.3.4 What problems are you experiencing in practice?

- Babies at risk are not directed to early intervention service routinely.
- Health professionals' awareness of early intervention is low. So that they don't direct babies to early intervention until certain developmental delay.
- Health system doesn't support early intervention until certain diagnosis.
- Community's early intervention awareness is low. They think the routine control of pediatrician is enough for screening developmental disorders.
- Parents leave early intervention due to financial and transportation difficulties.
- Early intervention is free but after a difficult and long process of diagnosis and educational report.
- Parents think that the health report will label their children.
- If babies catch up typical motor development, parents tend to leave early intervention.
- Grandfathers and mothers usually don't want to join early intervention service. They think that their babies will catch up typical development at school age.

### 2.3.5 What are the solutions for these problems that you have encountered?

- The awareness studies for community and health professionals are organized by using workshop, congress, social media.
- Workshops are organized for different health professionals working with babies.
- Funding by non-governmental organizations to therapy costs
- Master and PHd theses are published about early intervention.
- Local financial resources support scientific studies about early intervention
- As a result of workshop studies Turkish health professionals suggest that early intervention should be free for all babies at risk and don't requirement certain diagnosis.

### 2.4 Physiotherapist as a member of the early intervention team in Turkey?

The individuals who are accepted to a physiotherapy program were awarded as “physiotherapist” title by completing a total of 240 ECTS credits as a result of 4 years undergraduate education from the physiotherapy and rehabilitation departments of the universities. They are able to work in the field of pediatric physiotherapy and rehabilitation depending on their individual preference with their diploma after their undergraduate education. Turkey doesn't have a post graduate education in early intervention, as well as in pediatrics. Also we don't have a formal process for specialization in early intervention and pediatrics for physical therapists.

#### 2.4.1 Are there professional requirements for physiotherapists to take part in early intervention system?

Physiotherapists who want to be specialized in early intervention may follow the post-graduate courses offered by institutions and/or associations. They may also have some courses related to early intervention in some master or doctorate programs. Physiotherapy and rehabilitation education in Turkey is available in 58 universities (24 of them are states and 38 foundations) in 23 different cities.

In Turkey, however, there are several university hospitals – Gazi University, Hacettepe University, Marmara University, Dokuz Eylül University, Zeynep Kamil Training and Research Hospital, NGOs (e.g. the Spastic Children Foundation) and specialized centres with multidisciplinary teams offering early intervention programs for infants at risk and children with cerebral palsy. Physiotherapists may serve in the departments of neonatology offering these programs. They are working with the consultation of the neonatologists and neurologists in neonatal intensive care units as well as the daily services and departments. They may also take role as a part of the early intervention team in outpatient clinics and follow up departments for infants at risk.

#### 2.4.2 Do you have pediatric rehabilitation, early intervention, typical and atypical motor development etc. lessons which can be elective or compulsory in physiotherapists' undergraduate, postgraduate, and life learning program education? If possible, provide syllabus of the courses.

We have normal motor development and pediatric physiotherapy and rehabilitation courses in our undergraduate program, which are compulsory. On the other hand there are some elective courses

which is generally offered in the 5<sup>th</sup> and/or 6<sup>th</sup> semester such as, pediatric cardiopulmonary rehabilitation, facilitation methods in paediatrics, evaluation treatment in neonatal term, sensory, perception and motor evaluation treatment, functional exercises in pediatrics. There are also some courses in the postgraduate programs such as, principles of neurodevelopmental treatment, pediatric physiotherapy and rehabilitation, kinesiology of normal motor development, sensory integration therapy, muscle tone and its rehabilitation.

[http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders\\_kodu=116010001&sirali=0&fakulte=&fakulte\\_en=&bolum=&bolum\\_en=](http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders_kodu=116010001&sirali=0&fakulte=&fakulte_en=&bolum=&bolum_en=)

[http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders\\_kodu=1160098&sirali=0&fakulte=&fakulte\\_en=&bolum=&bolum\\_en=](http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders_kodu=1160098&sirali=0&fakulte=&fakulte_en=&bolum=&bolum_en=)

[http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders\\_kodu=316030012&sirali=0&fakulte=&fakulte\\_en=&bolum=&bolum\\_en=](http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders_kodu=316030012&sirali=0&fakulte=&fakulte_en=&bolum=&bolum_en=)

[http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders\\_kodu=316030015&sirali=0&fakulte=&fakulte\\_en=&bolum=&bolum\\_en=](http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders_kodu=316030015&sirali=0&fakulte=&fakulte_en=&bolum=&bolum_en=)

[http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders\\_kodu=316030019&sirali=0&fakulte=&fakulte\\_en=&bolum=&bolum\\_en=](http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders_kodu=316030019&sirali=0&fakulte=&fakulte_en=&bolum=&bolum_en=)

[http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders\\_kodu=316030021&sirali=0&fakulte=&fakulte\\_en=&bolum=&bolum\\_en=](http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?dr=0&lang=1&baslik=1&ac=16&FK=16&BK=30&ders_kodu=316030021&sirali=0&fakulte=&fakulte_en=&bolum=&bolum_en=)

[http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?baslik=1&dr=0&lang=0&ac=16&FK=16&BK=30&ders\\_kodu=316030022](http://gbp.gazi.edu.tr/htmlProgramHakkinda.php?baslik=1&dr=0&lang=0&ac=16&FK=16&BK=30&ders_kodu=316030022)

#### 2.4.3 How do you standardize the physiotherapy practices in early intervention?

Physiotherapy practices in early intervention is not standardised in our country. It is generally based on the expertise of the professionals guiding those departments offering early intervention programs. Vojta, Neurodevelopmental Treatment, Peto, Feldenkreise, Maes, Anat Baniel, Jeremy Krauss, Floortime, sensory integration therapy, goal oriented therapy are some forms/concepts of therapies that is used in Turkey. The practices in early intervention is also guided by the post graduate courses

in the framework of lifelong learning. But, the most commonly used intervention is neurodevelopmental treatment.

### 3. Early Childhood Intervention System in United Kingdom

#### Introductory note about this section

The report calls for a country report on the UK. However, The United Kingdom is a state made up of the historic countries of England, Wales and Scotland, as well as Northern Ireland. The Head of State is Her Majesty Queen Elizabeth II and the Prime Minister is Theresa May.

This section of the report will include as much information on Scotland, Wales and Northern Ireland as possible, however it should be noted that these countries have different early childhood education frameworks to England and to report in detail on each country would be onerous and outside the remit and time allowance for this report. For example there is a separate Scottish Parliament who have implemented a number of childcare Acts separate to England. There is a national assembly for Wales who have also drawn up various childcare and young people policies and a Northern Ireland Executive who also hold power for budgetary organisation and administration related to children, schools and families in NI.

In England the work of early years educators/professionals is supported by the Early Years Foundation Stage. This and the Healthy Child Programme require early childhood care and education providers to work closely with Health Visitors to conduct a two year old assessments (between the ages of 18 – 24 months usually) for children and report to parents about any developmental delays and difficulties. Additional support will be sought from area Special Educational Needs Co-ordinators (SENCOs) at this point as necessary. Every early childhood setting is required to have a named SENCO and the Local Authority must provide an Area SENCO to support early childhood providers. Children who are born with disabilities will be referred at the earliest stage to early intervention programmes, usually assessment and monitoring, as well as support from Physiotherapists/Occupational Therapists and other Paediatric professionals.

#### 3.1 The population of baby at risk and experts in United Kingdom

##### 3.1.1 What is the population of 0-3 year age babies, and baby at risk under 3 years of age?

The UK population is at its [largest ever at 65.6 million](#), compared with 65.1 million for 2015, a growth rate of 0.8% from 2015 to 2017. This is consistent with recent increases seen since 2005, which have varied between 0.6% and 0.8%. The provisional number of live births in the UK in 2016 was 774,849; a decrease of 0.3% compared with 2015. In Scotland the number of live births decreased by 1.1% in 2016 (provisional figure); there was a slightly smaller fall of 0.5% in Northern Ireland (provisional figure). There are over 11 million children under 18 in England (2017). Source: Office of National Statistics

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/articles/overviewoftheukpopulation/july2017>

At the same time Over 390,000 children received support from children's services in England in 2017 as discussed below:

**Table A3: Number of children in need at 31 March 2017, by gender, age (at 31 March) and primary need<sup>1</sup>**

Year: 2016-17

Coverage: England

[Statistics: children in need and child protection](#)

	Total children in need at 31 March 2017 <sup>2</sup>	N1 - Abuse or Neglect	N2 - Child's disability or illness	N3 - Parent's disability or illness	N4 - Family in acute stress	N5 - Family dysfunction	N6 - Socially unacceptable behaviour	N7 - Low income	N7-Absent parenting	N9 - Cases other than children in need	NO not stated	Missing
<b>Number of children in need at 31 March<sup>3,4</sup></b>	<b>389,430</b>	<b>203,750</b>	<b>36,790</b>	<b>10,870</b>	<b>36,000</b>	<b>62,340</b>	<b>7,890</b>	<b>1,670</b>	<b>12,190</b>	<b>3,590</b>	<b>14,270</b>	<b>70</b>
Of which:												
Unborn	6,980	4,114	59	339	496	1,280	62	8	21	38	555	x
Unknown gender <sup>3,4</sup>	680	325	18	18	61	86	8	x	6	x	150	x
Total Male <sup>4</sup>	206,260	101,700	24,260	5,390	18,900	31,770	4,760	900	9,600	1,870	7,070	30

Under 1	<b>10,150</b>	6,346	133	453	793	1,628	88	31	44	68	562	0
1-4 years	<b>36,590</b>	22,234	1,634	1,113	3,066	6,075	383	147	165	269	1,495	12
5-9 years	<b>52,740</b>	28,621	6,362	1,424	4,481	8,241	704	230	264	541	1,867	9
10-15 years	<b>65,360</b>	30,976	10,620	1,582	6,256	9,938	1,643	240	1,424	596	2,080	x
16 & over	<b>41,400</b>	13,523	5,515	821	4,305	5,889	1,942	255	7,703	390	1,054	x
<b>Total Female<sup>4</sup></b>	<b>175,500</b>	<b>97,610</b>	<b>12,450</b>	<b>5,120</b>	<b>16,540</b>	<b>29,200</b>	<b>3,060</b>	<b>750</b>	<b>2,560</b>	<b>1,680</b>	<b>6,500</b>	<b>30</b>
Under 1	<b>9,490</b>	5,940	138	400	743	1,544	70	32	24	57	536	x
1-4 years	<b>33,170</b>	20,179	1,054	1,092	2,702	5,808	356	135	146	235	1,454	6
5-9 years	<b>43,540</b>	25,271	3,103	1,267	3,666	7,195	568	183	226	422	1,631	8
10-15 years	<b>56,090</b>	30,570	5,193	1,553	5,405	8,829	1,188	221	577	576	1,973	8
16 & over	<b>33,210</b>	15,650	2,959	808	4,023	5,821	877	182	1,591	388	905	9

**Notes:**

Source:  
Children in  
need census

1. The main reason why the child started to receive services is recorded as their primary need.

2. Sub totals/totals are rounded to the nearest 10. Sub totals may not add up to totals due to rounding.

Source <https://www.gov.uk/government/collections/statistics-children-in-need>

In England, around 10,000 children are born very preterm and a further 60,000 are born moderately preterm. The number of multiple births (where there is also risk to development is shown below:

Multiple Births statistics in the UK for 2016:

	England & Wales (ONS London)	Scotland (GRO Scotland)	N.Ireland (NISRA)	UK Total
<b>Total Maternities</b>	696,271	54,488	725	774,530
<b>All multiples</b>	10,951	815	373	12,139
<b>Twins</b>	10,786	804	359	11,949
<b>Triplets</b>	160	11	14	185
<b>Quads and more</b>	5	Not Listed	Not Listed	5
<b>Twinning rate/1000 mats</b>	15.49	14.76	15.10	15.67
<b>Triplet rate/1000mat</b>	0.23	0.20	0.59	0.24
<b>Multiple Birth Rate/1000 mats</b>	15.73	14.96	15.69	15.67

Obtained from the [Office for National Statistics](#), [General Registry Office Scotland](#) and [GRO Northern Ireland](#).

### 3.1.2 What is the population of school age children with motor, cognitive, speech and social problem?

In England, the number of pupils with special educational needs (SEN) has increased from 1,228,785 in January 2016 to 1,244,255 in January 2017. While this is the first annual increase since 2010, the percentage of pupils with SEN remains stable at 14.4%. 242,185 pupils have a statement of SEN or an Education, Health and Care (EHC) plan (a Statement or EHC plan describes the child's SEN and plan of provision/entitlement). This is an increase of 5,380 since January 2016, but remains equal to 2.8% of the total pupil population. A further 1,002,070 pupils are on SEN support. This is equal to 11.6% of the total pupil population and remains unchanged since January 2016. Moderate Learning Difficulty is the most common primary type of need overall, as was the case in January 2015 and January 2016. 22.7% of pupils

with special educational needs have this primary type of need in January 2017. This percentage has decreased from 24.2% in January 2016. Moderate Learning Difficulty is also the most common type of need for pupils on SEN support; 25.2% of pupils on SEN support had this primary type of need in January 2017. Autistic Spectrum Disorder remains the most common primary type of need for pupils with a statement or EHC plan, with 26.9% of pupils with a statement or EHC plan had this primary type of need in January 2017. This has increased from 25.9% in January 2016.

SEN is reported/categorized according to discrete but sometimes overlapping categories as shown below (for example SLCN overlaps with ASD):

Children on SEN Support	Primary Type of Need	Statement or EHC Plan
15.1	Specific Learning Difficulty	3.7
25.2	Moderate Learning Difficulty	12.6
0.4	Severe Learning Difficulty	12.9
0.1	Profound & Multiple Learning Difficulty	4.4
17.3	Social, Emotional and Mental Health	12.4
22.0	Speech, Language and Communications Needs	14.3
1.7	Hearing Impairment	2.6
0.9	Visual Impairment	1.4
0.2	Multi-Sensory Impairment	0.3
2.3	Physical Disability	5.6
5.2	Autistic Spectrum Disorder	26.9
5.3	Other Difficulty/Disability	2.5

**Figure B:** Percentage of pupils with each primary type of need who are identified as SEN (either on SEN support or with a statement or EHC plan) in state funded primary, secondary and special schools Source: England, January 2017 Source: DfE Statistical Release <https://www.gov.uk/government/statistics/special-educational-needs-in-england-january-2017>

The four main categories of SEND described in the SEN Code of practice would be:

- Communication and interaction
- Cognition and learning

- Social, emotional and mental health difficulties
- Sensory and/or physical needs

### 3.1.3 What is the proportion of the expert dealing with baby at risk?

In England, this depends on the at risk category – possible experts include a wide range of professionals, including but not limited to:

Health Visitors

Social Workers

General Practitioners (GPs)

Early Years Teachers/Educators

Paediatricians

Educational Psychologists

Clinical Psychologists

Occupational Therapists

Physiotherapists

Charity Workers (for example Barnardo, NSPCC, Homestart, Pre-school Learning Alliance)

Play Workers

Music Therapists

Speech and language therapists

Family support workers

## 3.2 The Early Intervention Process in United Kingdom

In England children's rights are now enshrined in the Children and Families Act 2014. The act brought changes to the law to give greater protection to vulnerable children, better support for children whose parents are separating, a new system to help children with special educational needs and disabilities, and help for parents to balance work and family life. Under the Act the Local Authority has a duty to the children and families in their area as follows:

- (1) A child or young person has special educational needs if he or she has a learning difficulty or disability which calls for special educational provision to be made for him or her.
- (2) A child of compulsory school age or a young person has a learning difficulty or disability if he or she—
  - (a) has a significantly greater difficulty in learning than the majority of others of the same age, or
  - (b) has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions.
- (3) A child under compulsory school age has a learning difficulty or disability if he or she is likely to be within subsection (2) when of compulsory school age (or would be likely, if no special educational provision were made).
- (4) A child or young person does not have a learning difficulty or disability solely because the language (or form of language) in which he or she is or will be taught is different from a language (or form of language) which is or has been spoken at home.

### **Special educational provision, health care provision and social care provision**

- (1) “Special educational provision”, for a child aged two or more or a young person, means educational or training provision that is additional to, or different from, that made generally for others of the same age in—
  - (a) mainstream schools in England,
  - (b) maintained nursery schools in England,
  - (c) mainstream post-16 institutions in England, or
  - (d) places in England at which relevant early years education is provided.
- (2) “Special educational provision”, for a child aged under two, means educational provision of any kind.
- (3) “Health care provision” means the provision of health care services as part of the comprehensive health service in England continued under section 1(1) of the National Health Service Act 2006.
- (4) “Social care provision” means the provision made by a local authority in the exercise of its social services functions.
- (5) Health care provision or social care provision which educates or trains a child or young person is to be treated as special educational provision (instead of health care provision or social care provision).

### **Identifying children and young people with special educational needs and disabilities**

A local authority in England must exercise its functions with a view to securing that it identifies—

- (a) all the children and young people in its area who have or may have special educational needs, and

(b) all the children and young people in its area who have a disability.

### **23 Duty of health bodies to bring certain children to local authority's attention**

(1) This section applies where, in the course of exercising functions in relation to a child who is under compulsory school age, a clinical commissioning group,

NHS trust or NHS foundation trust form the opinion that the child has (or probably has) special educational needs or a disability.

(2) The group or trust must—

(a) inform the child's parent of their opinion and of their duty under subsection (3), and

(b) give the child's parent an opportunity to discuss their opinion with an officer of the group or trust.

(3) The group or trust must then bring their opinion to the attention of the appropriate local authority in England.

(4) If the group or trust think a particular voluntary organisation is likely to be able to give the parent advice or assistance in connection with any special educational needs or disability the child may have, they must inform the parent of that.

In early years settings and schools, the Act is further supported further supported by the SEN Code of Practice <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> and the Early Years Foundation Stage in England <https://www.gov.uk/early-years-foundation-stage>, the Early Years Framework in Scotland <https://beta.gov.scot/publications/early-years-framework/> and the Foundation Phase in Wales <https://gov.wales/topics/educationandskills/foundation-phase/?lang=en> The Learning to Learn framework applies to Northern Ireland <https://www.education-ni.gov.uk/articles/learning-learn>

Children can be referred to early intervention by parents and education, health and social care professionals. The most likely referral pathways are via health visitors, GPs and early years educators/teachers. Depending on the type of difficulty they may be referred to a child development centre for assessment or to specialist services if their difficulty is more clearly identifiable and the type of support needed clear.

#### **3.2.1 How a baby join early intervention system?**

This can vary from one local authority to another. Usually a referral is made to a child development centre. This is an integrated service is for pre-school children with physical or developmental delay who may need additional help, support or intervention in order to reach their potential. If children show delay in development in two or more areas, for example physical development and speech development they may need to be assessed at the Child Development Centre. Referrals are usually accepted from all children's health professionals, general practitioners and those working in children's pre-school settings.

A range of professionals offer assessment and intervention for children who are referred. Staff work in partnership with the child's parent/carer and there is a clear assessment process in place for children. The Child Development Centres are supportive and inclusive and take into account other services available to children in the community. The service offers an integrated and coordinated approach for children using a "Team around the Family" ethos. This involves a range of health professionals, who will work together to deliver a comprehensive package of care for children.

### 3.2.2 Is early intervention mandatory for babies at risk?

Parents can choose whether their child joins an early intervention programme. However, children's rights are defined by the UNCRC and social workers will intervene as appropriate where children's development/life is thought to be under extreme risk.

### 3.2.3 Is there eligibility criteria for participating in an early intervention program? What is the criteria?

Usually two or more areas of developmental delay/disability are called for. However, if children have been known to be exposed to risk, for example alcohol or drugs in the womb, or are born with a known and obvious disability such as Down's Syndrome, then referral is more straight forward.

### 3.2.4 How to decide which discipline will support the babies and their families?

This is based on a rigorous multi-disciplinary assessment. It is generally advised that not too many professionals will be involved at one time to avoid over-whelming families and also to simplify assessment of interventions as it can become very difficult to identify what works best when too many approaches are delivered at once.

### 3.2.5 Which institute support financially early intervention program and until when?

Under the Children and Families Act and the SEN Code of Practice Local Authorities are supposed to form Joining Commissioning initiatives for children's single Education, Health and Care plan. However, in reality this has not necessarily been implemented in all areas. Therefore, according to the particular type of intervention, single departments will fund. For example, for special education the school will fund from its budget with extra funding being available according to a child's needs and the number of children in a school with needs. For health intervention such as physiotherapy/occupational therapy/speech and language therapy, funding comes from the local NHS Trust fund.

### 3.2.6 Which experts work in the early intervention system and what are the roles?

In England, this depends on the specific difficulties the child experiences– possible experts include a wide range of professionals, including but not limited to:

Health Visitors - Health visitors are qualified and registered nurses or midwives who have chosen to gain additional training and qualifications as [specialist community public health nurses](#) (SCPHN - HV). Their additional training in public health enables them to assess the health needs of individuals, families and the wider community to promote good health and prevent illness. They work with early years teachers and GPs to refer children identified as at risk or with problems to other professionals.

**Social Workers** - Social workers work with individuals and families to help improve outcomes in their lives. This may be helping to protect vulnerable people from harm or abuse or supporting people to live independently. Social workers support people, act as advocates and direct people to the services they may require. Social workers often work in multi-disciplinary teams alongside health and education professionals.

**Family support workers** – family support workers offer practical help and emotional support to families experiencing short or long-term difficulties. They could be employed by local authorities' social services departments or charitable organisations. The focus of the role is to provide support to service users, empowering them to address various challenges, reducing problems and risks and, in some cases, helping to make sure that children can remain with their family.

**General Practitioners (GPs)** - General practitioners (GPs) treat all common medical conditions and refer patients to hospitals and other medical services for urgent and specialist treatment. They focus on the health of the whole person combining physical, psychological and social aspects of care.

**Early Years Teachers/Educators** – EYTs are responsible for planning and delivering an appropriate curriculum to support young children's learning and development and help them to transition to compulsory education at the age of five.

**Paediatricians** -

- general paediatrics - a hospital role covering children from birth to the age of 16. Most paediatricians have this generalist role
- neonatology - this role specialises in looking after newly born babies. It is usually based in an [intensive care](#) unit looking after premature babies or those with problems at birth
- community paediatrics - these doctors are based in the community and look after children with developmental, social or behavioural problems and those with a physical disability
- [paediatric cardiology](#) - this is a small area which is a specialty in its own right. These doctors diagnose and treat children with cardiac (heart) conditions

**Educational Psychologists** - Educational psychologists support children with challenges such as learning difficulties, social and emotional problems, issues around disability as well as more complex developmental disorders. They work in a variety of ways including observations, interviews and assessments and offer consultation, advice and support to teachers, parents, the wider community as well as the young people concerned.

**Clinical Psychologists** - treat people whose thought patterns and behaviour are a threat to their own and others' wellbeing. They assess and provide treatment for people with a wide range of conditions such as depression, eating disorders and addiction.

Specialist Teachers for Communication, Autism, Hearing Impairment, Vision Impairment – provide specialist teaching and pedagogical advice to mainstream teachers about particular and specific difficulties in their specialist area.

Occupational Therapists - help people of all ages to improve their ability to perform tasks in their daily living and working environments. They work with individuals who have conditions that are mentally, physically, developmentally, socially or emotionally disabling

Physiotherapists - is one of the allied health professions that, by using mechanical force and movements, manual therapy, exercise therapy, and electrotherapy, remediates impairments and promotes mobility and function. Physical therapy is used to improve a patient's quality of life through examination, diagnosis, prognosis and physical intervention.

Play Workers - Playwork is the work of creating and maintaining spaces for children to play. The theory and practice of playwork recognises that children's play should ideally be 'freely chosen, personally directed and intrinsically motivated.' For children with SEND, play workers often work in the home to support parent-child play opportunities or work to support children's socio-emotional development where this is thought to be at risk for example children with autism.

Music Therapists - Music therapists use music and sound to help improve people's emotional well being, relieve stress and improve confidence.

Speech and language therapists – SLTs provide treatment, support and care for children and adults who have difficulties with communication, or with eating, drinking and swallowing.

Portage workers - Portage is a home-visiting educational service for pre-school children with additional support needs and their families. The three essential elements in the Portage model are: Family Focus, Structured Teaching and Child Led Play.

Charity Workers (for example Barnardo, NSPCC, Homestart, Pre-school Learning Alliance) – they might offer practical support in the home, financial support to buy specialist equipment or friendship and advocacy services to families.

### 3.3 Early intervention as a policy in United Kingdom

#### 3.3.1 When and how did early intervention support start in your country?

Early intervention as a socially constructed and nationally available concept commenced with the foundation of the National Health Service on 5<sup>th</sup> July 1948. During this period of time, early intervention focused on health and social welfare.

Early years settings and nurseries were provided by Social Workers rather than education professionals. In terms of education, a number of education acts (1921, 1944) had described different kinds of disability and stipulated that all children must attend school except for the 'uneducable' and the Health Authority were to be responsible for the severely subnormal. 11 categories of 'handicap' were outlined which was

an increase from the previous 5 between 1921 and 1944. The Health Authority was responsible for the 'severely subnormal'. In 1970 an Education Handicapped Children Act and a Chronically Sick and Disabled Persons Act resulted in the requirement for all children to be registered with the Local Education Authority and for the LEA to keep a register of disabled people and to provide services for them.

A landmark report by Mary Warnock in 1978 changed early intervention in England. For the first time the term SEN was mentioned. She recommended that the Government replaced the 11 categories of 'handicap'. A five-stage approach for recognition and assessment was established and the integration of SEN into mainstream schools considered.

In 1989 a child rights approach introduced a register of 'children in need' with the introduction of a new Children Act. This was closely followed by a new Education Act in 1993 which promoted the education of children with SEN in mainstream schools firmly placing the responsibility for SEN/D with education. By 1994 schools were required to identify a Special Educational Needs Co-ordinator to support children with SEN following the UNESCO Salamanca statement. This was followed in 2001 with a new SEN Code of Practice that was designed to provide a legislative framework for schools and early years settings. The Special education needs and disability Act of 2001 strengthened the rights of parents and children to mainstream education.

As far as early years and early intervention is concerned, integrated early childhood services were introduced by New Labour from 1997 onwards in order to reduce the number of children living in poverty, the number of children with SEND and the number of children with poor language and cognition outcomes. Children's Centres were introduced and expanded along with a number of other control and support measures for families at risk. Children's centres followed a multi-disciplinary approach to early care and education and included support for families in terms of employment and financial advice, early intervention services and maternity services.

Further to this *Together from the Start* and the *Early Support Programme* focused on co-ordinated services for children under the age of three and their families through children's centres. The aim was to:

- promote effective early intervention services for meeting the needs of very young disabled children and their families;
- to identify and promote existing good examples of effective partnership working; and
- to support the strategic development of services for this population.

The introduction of the *Every Child Matters [ECM]* in 2004 and the *Children Act 2004* were significant policy development programmes for children and families as a result of the Laming Report into child abuse and child protection. Significant investment was placed in achieving the stated aims of *ECM*. These were for all children to:

- be healthy;
- stay safe;
- enjoy and achieve;
- make a positive contribution to community and society, and not engage in anti-social behaviour;
- achieve economic well-being that is, not being prevented by economic disadvantage from reaching full potential in life.

Funding for childcare was provided for all children aged three and four years old of upto fifteen hours per week to facilitate maternal employment and improve children's language and cognition outcomes. Early childhood provision became increasingly regulated and training for professionals who worked in early childhood care and education was improved and subsidised through Local Authorities (LAs) and early years partnerships. The provision of a range of high-quality early childhood provision became a key government and LA target so that parents and families had choice of provision and that there was sufficient provision to meet the needs of all children.

Currently in England the rights of young children (aged birth to five) with developmental delays and disabilities are embodied within The Special Educational Needs and Disability Code of Practice: 0 to 25 years (2014) (CoP) and Part 3 of the Children and Families Act, published in 2014 both of which relate to provision for children with SEND.

Early childhood providers must have regard for the revised CoP and ensure that they also comply with associated duties in the:

- Equality Act (GB 2010)
- Early Years Foundation Stage (DfE 2014)
- Working Together to Safeguard Children (DfE, 2015).

Professional responsibility of early childhood practitioners who work with young children is to focus on EI, joined-up working with other professionals and parent engagement. Practitioners are also required to undertake an assessment of two-year-olds' learning and development jointly with Health Visitors (HVs) with a summary of progress being provided to parents through the Healthy Child Programme run by HVs (DCSF/DH, 2008). The Bill and CoP are cornerstones of recent SEND reforms, the aspiration for which was the equal participation of children, young people and their parents in decisions being made about local services, and a focus on improving education and outcomes for children and young people. The Code (section 5.1) states that:

...all children are entitled to an education that enables them to achieve the best possible educational and other outcomes.

There is also a responsibility of duty on LAs to set out in their Local Offer including funding arrangements for early years education and what early childhood care and education providers are expected to make available to children with SEND and their families. Operating as an organising document for services to work together is a new co-ordinated assessment process and Education, Health and Care (EHC) plan to replace assessments and statements for children with more complex needs. Further to this there is a new Early Intervention Foundation (<http://www.eif.org.uk/>) whose mission is to champion and support the effective use of EI to tackle the root causes of social problems for children from conception to early adulthood with a focus on EI that is shown to improve the social and emotional development of children and young people. Their early childhood work focuses on parent-child relationships in the home.

The majority of children's centres have been closed in the last five years due to austerity measures. Some local authorities do not have any children's centres at all currently.

### 3.3.2 Is there any structured early intervention program in your country?

There are a number of different structured programmes available in different Local Authorities. For example:

- Parenting early intervention programme (PEIP) to help parents with parenting skills
- The PEEP Learning Together Programme by Peeple is for parents with a child between birth and age five.
- The Incredible Years helps parents support their child's socio-emotional-behavioural development
- Mellow Toddlers is a group-based programme delivered to mothers or fathers (separate groups for each) with identified parenting difficulties and who have a child between the ages of one and three.
- Nobody Slips Through the Net (or Keiner Fällt Durchs Netz, KfdN) is a German home-visiting programme delivered by trained family midwives to parents identified as having multiple risks
- Child First is a home-based, therapeutic intervention targeting young children at risk of emotional problems, developmental delay, and abuse and neglect.
- Let's Play in Tandem is a school-readiness programme for children aged three living in socially disadvantaged communities. It aims to improve children's cognitive development and self-regulation.
- Circle of Security (COS) was developed to increase attachment security among socially disadvantaged children between the ages of one and five.
- Nurture Groups – Classic Boxall Model is a short-term intervention grounded in Bowlby's attachment theory, which aims to address barriers to learning arising from unmet attachment needs.

- The PATHS® Preschool/Kindergarten curriculum promotes emotional and social competencies and reduces aggression and behaviour problems in preschool/kindergarten-aged children, while simultaneously enhancing the educational process in the classroom.
- Family Nurse Partnership offers intensive and structured home visiting centred on attachment, relationships and healthier lifestyles, delivered by specially trained nurses
- Empowering Parents, Empowering Communities (EPEC) is for disadvantaged families experiencing behavioural difficulties with a child between the ages of two and 11.
- 5 Pillars of Parenting (4–11 Years) is a targeted-selected programme, aimed at Muslim parents with a child between the ages of 4 and 11 years.
- Hitkashrut is an Israeli programme targeting children between the ages of three and five with identified behavioural difficulties.
- The Family Check-up (FCU) for Children is a strengths-based, family-centred intervention that motivates parents to use parenting practices to support child competence, mental health and risk reduction.
- Time to Talk to helps children with speech, language and communication skills (can be delivered by teachers/therapists)
- Early Bird helps parents of children diagnosed with autism
- Dare to be You (DTBY) aims to reduce the likelihood of adolescent substance misuse by promoting family resilience in at-risk families with a child between the ages of two and five years old.
- The Lidcombe Programme is for parents with a child (aged three to six) with a diagnosed stuttering problem.
- The New Forest Parenting Programme (NFPP) is for parents with a child between the ages of three and 11 with moderate to severe symptoms of ADHD.
- The Solihull Approach Parenting Group (also known as Understanding Your Child's Behaviour) is a universal parenting intervention for any parent with a child between the ages of 0 and 18.
- Families and Schools Together (FAST) Preschool is a group-based intervention for parents of a preschool child who wish to support their child and become more engaged in their community. It can operate at a universal level, but is more frequently provided on a targeted basis to families where there is an elevated risk of child behavioural problems.
- Zippy's Friends is a universal school-based programme for children between the ages of five and seven.

- Stepping Stones Triple P has been developed for parents or caregivers of children aged 0 to 12 with a developmental disability, such as Down's Syndrome or Autistic Spectrum Disorder. Group Stepping Stones Triple P is one mode of implementation of the Stepping Stones programmes.

However, where children have identified risk factors or a diagnosed disability they are more likely to be referred to a child development centre for assessment and multi-disciplinary support rather than attend a structured early intervention programme.

### 3.3.3 What are the procedural responsibilities of early intervention practitioners? (Reporting and registration)

This depends on the discipline in which their work is contextualized. For most professionals there is an organizing body (e.g. the Royal College of Speech and Language Therapists, the College of Teaching) with whom the professionals must register annually. Professionals are supervised by line managers and there are codes of conduct that guide their work with children and families (e.g. the Teaching Standards).

### 3.3.4 What problems are you experiencing in practice?

In practice there are problems with over-regulation and rigorous inspection regimes that often imply onerous paperwork that reduces the amount of time for interacting with children/families and sometimes stifles creativity.

### 3.3.5 What are the solutions for these problems that you have encountered?

A most common solution is that professionals experience burnout quite early in their careers and leave their profession/retire early. There are shortages in the number of health visitors, midwives, GPs and teachers currently.

## 3.4 Physiotherapist as a member of the early intervention team in United Kingdom?

### 3.4.1 Are there professional requirements for physiotherapists to take part in early intervention system?

This decision will be based on a child assessment and integrated professional plan for support. If a child has motor/physical developmental problems, then an occupational/physiotherapist will be assigned to the team based on a referral to the local physiotherapy team. It is not a basic requirement for all children to be assigned a Physiotherapist or for every team around the child to have a Physiotherapist on board.

### 3.4.2 Do you have pediatric rehabilitation, early intervention, typical and atypical motor development etc. lessons which can be elective or compulsory in physiotherapists' undergraduate, postgraduate, and life learning program education? If possible provide syllabus of the courses.

37 Academic Institutions offer undergraduate Physiotherapy programmes and some also offer post-graduate programmes. Each has their programme and method of delivery. There is also a Chartered Society of Physiotherapy which is the professional, educational and trade union body for the England's 57,000 chartered physiotherapists, physiotherapy students and assistants.

Physiotherapy programmes accredited with the Chartered Society of Physiotherapy are expected to show that they are changing in response to evolving patterns of service delivery and addressing the particular needs of their local population. Whilst the CSP expects physiotherapy graduates to understand the needs of individual service users, the CSP does not list particular

conditions/disorders/pathologies/syndromes that students need to know about nor does it prescribe modalities and approaches used. We do however expect teams to demonstrate that their graduates have currency within health and social care environments.

Rather, programme teams are expected to demonstrate that new graduates will have an understanding of a range of factors (pathological, social, environmental, physical, emotional, psychological etc.) which influence how individual patients may present and react to physiotherapy and how to adapt physiotherapy modalities and approaches appropriately. However, most importantly, the CSP seeks reassurance from programme teams that physiotherapy students, within the university and on practice placements, are being equipped to pro-actively, independently and continually advance their knowledge and skills throughout their careers in response to changes in service delivery and the changing needs of the population.

Attached is a L&D principles which although doesn't prescribe, does give an indication of what the CSP would be looking to see drawn out within a programme. CSP then uses the programme (re)accreditation events to explore these issues with programme teams in depth. This is important because each team will approach their curriculum differently - some dedicate modules, others thread content through each year, returning to it at a number of points so it is difficult to provide you with a definitive what they are taught and when. What we are looking for is the end point which is where the final attachment comes in, is by the end of the programme all graduates must be able to meet these outcomes (And HCPC standards of proficiency).

There is an APCP Introduction to Paediatric Physiotherapy 2018 organised by the Association of Paediatric Chartered Physiotherapy. This 3-day course is for physiotherapists who are new to working with children and young people, including newly qualified physiotherapists, those changing from another speciality, or those returning to practice and wishing to work in paediatrics.

The course may also be suitable for experienced support workers and other AHP's who work within paediatrics - however, this will be at the discretion of their managers when considering learning needs.

The learning objectives for this course:

- 1) Demonstrate an in-depth understanding of the context within which a paediatric physiotherapist practices - this will include communication with children, young people and their families, partnership working, consent and legal issues.
- 2) Demonstrate an understanding of the impact of diagnosis (to include differential diagnosis), adjustment and prognosis on child, family and therapist.
- 3) Critically analyse components of normal childhood development, which relate particularly to paediatric physiotherapy practice - this will include growth and musculoskeletal development, respiratory development, and normal variants.
- 4) Demonstrate basic knowledge of appropriate paediatric assessment methods.

- 5) Demonstrate basic knowledge of interventions to enable a practitioner to select and apply the appropriate treatment strategies for a child's age and condition.
- 6) Understand and identify any precautions and contraindications to treatment techniques.
- 7) Write an effective plan for the child's age and condition taking cognisance of prognosis including the selection of appropriate outcome measures, management and treatment methods.
- 8) Demonstrate an awareness of current practice supported by evidence over a wide variety of clinical areas.

The Association of Paediatric Chartered Physiotherapy also offer a Cerebral Palsy Integrated Pathway for Physiotherapists across the UK. The pathway involves a nationally agreed protocol of standardised musculoskeletal examination for children with CP to ensure equity throughout Scotland. It is based on best practice guidelines from Sweden and Australia and meets the principles of care recommended in the 2012 NICE Clinical Guideline 'Spasticity in children and young people with non-progressive brain disorders'

#### 3.4.3 How do you standardize the physiotherapy practices in early intervention?

There is a Chartered Society of Physiotherapy <http://www.csp.org.uk/professional-union/careers-development/career-physiotherapy> and health and care professions council <http://www.hpc-uk.org/> who organize and oversee/regulate Physiotherapy practice at a national level. Further to this, individual NHS and Local Commissioning Trusts will oversee practice within different practice institutions.

## 4. Early Childhood Intervention System in Portugal

### 4.1 The population of baby at risk and experts in Portugal

#### 4.1.1 What is the population of 0-3 year age babies, and baby at risk under 3 years of age?

According to Institute of National Statistics (2015), Portugal has been decreasing its crude birth rate since 2000 from 12% to 7.9% in 2014. The number of children born in 2018 were 41.553. In 2014 there was 259.626 children between ages 0 to 3 years of age. We had 265.414 children enrolled in Pre-School education (3-5 years), and this means a Pre-primary crude educational attainment rate of 89.8 % (Ministry of Education and Science - Directorate-General for Education and Science, INE, 2014).

When the System was established, one of the first reports that came out, mentioned that there was 7.545 children, being served in 2011. Data from Portuguese National System of Early Intervention in Childhood (SNIPI) Reports, noted that between 2011 and 2012 there was 55% increase in the number of children being served by SNIPI and between 2012 and 2013 there was a 22% increase of children being served (Serrano et al., 2017). Currently there are 20.041 children being followed by SNIPI which develops early intervention services for children from birth to six years old. There are 5.313 children from birth to 3 years of age and 14.728 children from 3 to 6 years of age.

#### 4.1.2 What is the population of school age children with motor, cognitive, speech and social problem?

In 2015-16 there were 79077 students identified with special needs in the school system.

#### 4.1.3 What is the proportion of the expert dealing with baby at risk?

There is approximately 1 professional for 10 children in the early intervention teams of the SNIPI. This professional functions on a transdisciplinary model and functions as a mediator between the family and the support and knowledge of the different professionals in the team.

### 4.2 The Early Intervention Process in Portugal

#### 4.2.1 How a baby join early intervention system?

According to the legislation that established the SNIPI, the entrance door to the system is the health system, who should ensure the detection, signaling and referring of the EI process, but a child can be referred to the SNIPI by any person (parents, early childhood educators, etc.) using an appropriate referral form available on the official website of the SNIPI. The referral form is sent directly to the local early intervention team with information about the child, its parents, the referral reasons and current specialized support.

#### 4.2.2 Is early intervention mandatory for babies at risk?

The early intervention support provided by the SNIPI early intervention teams is not mandatory. Parents can decide whether they want or refuse EI services as long as their child's rights and life are not in danger. Nevertheless, the absence of EI for babies at environmental risk may constitute a situation of neglect or mistreatment and in these situations the early intervention support may be compulsory by children's protective services.

#### 4.2.3 Is there eligibility criteria for participating in an early intervention program? What is the criteria?

There is eligibility criteria for children to integrate the SNIPI. The Decree-Law No. 281, of October 6 that created the SNIPI and the Local Intervention Teams (ELI) established that there are eligible for support under the SNIPI, children between the ages of 0 and 6 and their families, with characteristics included in the following groups:

1. **"Changes in body functions or structures"** that limit normal development and participation in typical activities, considering the development patterns for their age and social context;
2. **"Serious risk of developmental delay"** due to the existence of biological, psycho-affective or environmental factors which imply a high probability of relevant delays in the development.

There are eligible all children included in the first group (Changes in body functions or structures). Children in the second group (Serious risk of developmental delay) must accumulate four or more biological and/or environmental risk factors.

The eligibility criteria for each group is the following:

##### 1. Children with changes in body functions or structures

**1.1. Developmental Delay with no known etiology**, covering one or more areas (motor, physical, cognitive, language and communication, emotional, social and adaptive), validated by a reasoned assessment, made by a competent professional.

**1.2. Specific Conditions** - They are based on a diagnosis related to situations that are developmental delays, among others:

- Chromosomal anomaly (Trisomy 21, Trisomy 18, X-Fragil Syndrome)
- Neurological disorders (cerebral palsy, neurofibromatosis)
- Congenital malformations (polymorphic syndromes)
- Metabolic disease (mucopolysaccharidoses, glycogenoses)
- Sensory deficit (low vision / blindness, deafness)
- Disorders related to prenatal exposure to teratogenic agents or to narcotics, cocaine and other drugs (fetal alcohol syndrome)
- Disorders related to severe congenital infections (HIV, TORCH, meningitis)
- Severe chronic disease (CNS tumors, renal D., hematologic D.)
- Atypical development with changes in the relationship and communication (autism spectrum disorders)
- Severe bonding disorders and other emotional disturbances.

## 2. Children with Serious Developmental Delay Risk

**2.1. Children exposed to biological risk factors:** Includes children who are at risk of developing limitations in activity and participation (ICF - CY, 2007) due to conditions that clearly interfere with basic care, health and development. It might be a diagnosis related to, among others:

- A family history of genetic abnormalities, associated with development;
- Intrauterine exposure to toxins (alcohol, drugs of abuse);
- Severe prenatal complications (hypertension, toxemia, infections, bleeding, etc.)
- Prematurity <33 weeks of gestation;
- Very low birth weight (<1.5 kg);
- Intrauterine Growth Delay: Birth weight <10th percentile for gestation time;
- Severe perinatal asphyxia (Apgar at 5 minutes <4 or cord blood pH <7.2 or neurological or organic systemic manifestations).
- Serious neonatal complications (sepsis, meningitis, metabolic or hydro-electrolytic, convulsions)
- Intra-ventricular hemorrhage;
- Congenital infections (TORCH Group);
- HIV positive child
- Severe central nervous system infections (bacterial meningitis, meningo-encephalitis)
- Severe cranial injuries
- Chronic otitis with hearing loss risk

### 2.2. Children exposed to environmental risk factors

Environmental risk conditions are considered to be the existence of parents or contexts that act as an obstacle to the child's activity and participation, limiting the development opportunities and making the well-being impossible.

#### 2.2.1. Parental risk factors are, among others:

- Adolescent mothers <18 years old
- Alcohol abuse or other addictive substances
- Active maltreatment (physical, emotional and sexual abuse) and neglect of the basic child care (health, food, hygiene and education)
- Psychiatric disease
- Disabling or limiting physical illness

#### 2.2.2. Contextual factors are, among others:

- Isolation (difficulty in accessing formal and informal services; socio-cultural and ethnic, racial or sexual discrimination; religious discrimination; unemployment; families beneficiaries of financial or social support)
- Family disorganization (frequent family conflict; poor space organization and hygiene);

- Significant concerns expressed by one parent, child or health care provider in relation to the development of parental style or parent-child interaction

#### 4.2.4 How to decide which discipline will support the babies and their families?

The ELI of the SNIPI are coordinated by a member nominated by the regional SNIPI commission. The coordination of the disciplines supporting children and their families is defined by the team coordinator.

#### 4.2.5 Which institute support financially early intervention program and until when?

In Portugal the SNIPI is entirely public funded. The access to the services of the ELI is free for the children and their families.

Considering the financing of SNIPI, within the scope of competencies legally attributed to the Social Services Ministry, one of the main instruments of action has been the cooperation agreements of ECI with Private Institutions of Social Solidarity (IPSS), for the purpose of hiring social workers, therapists and psychologists who integrate ELI teams. The financing of the cooperation agreements is based on the validated references by the SNIPI National Coordination Commission and there is an established value per child according to different typologies, which depends on the number of children and professionals in the team. The other two Ministries, Health and Education provide human resources (doctors, nurses, early childhood special educators, etc.).

#### 4.2.6 Which experts work in the early intervention system and what are the roles?

The professionals working in the early intervention system possess a diversified background and are placed in the ELI preceding from different organisms under the tutelage of the three Ministries responsible for the SNIPI (Health, Education and Science and Solidarity, Employment and Social Security), forming in this way, a multidisciplinary team composed, among others, by professionals related to children development namely by doctors, nurses, therapists (physiotherapists, speech therapist and occupational therapist), psychologists, childhood educators, teachers and social workers. The teams may also include professionals from local authorities or from other institutions that have professionals with experience in this area.

The main roles of the professionals in the ELI are the following:

- Identify children and families eligible to be supported immediately by the SNIPI;
- Ensure the monitoring of children and families that, although not immediately eligible, require periodic assessment, owing to the nature of their risk factors and likelihood of progress;
- Refer children and families who are not eligible, but lack social support;
- Elaborate and execute the Individual Plan for Early Intervention (PIIP), depending on the diagnosis of the situation;
- Identify the needs and resources of the communities in their area of intervention, stimulating formal and informal networks of social support;

- Articulate, whenever appropriate, with child protection services, with the health services or other entities with duties in the area of child protection;
- Ensure, for each child, appropriate transition processes for other educational programs, services or contexts;
- Coordinate with the teachers of kindergartens in which the children integrated.

### 4.3 Early intervention as a policy in Portugal

#### 4.3.1 When and how did early intervention support start in your country?

According to Ruivo & Almeida (2002), the first specific legislation for Early Intervention (EI) in Portugal emerged in 1999 through Joint Executive Regulation 891/99, dated October 19. Until then, the legislation that framed EI in Portugal was distributed in the diplomas referring to special education and pre-school education. Despite this limitation until the end of the 1990s, the 1980s were the decade of the emergence of EI in Portugal. One of the first programs came in the mid-1980s with the implementation of the Portage Model for parents by the Department of Psychological Orientation and Intervention Services (DESOIP), under the Social Security in Lisbon. This program and others, where structured on the notion of being child centered, were organizationally isolated and functioned in an individual way. This lack of articulation with other services that also serve the needs of children and families, e.g. social services, health services, educational services, and justice among others led to fragmented service delivery.

Subsequently, the Integrated Intervention Project for the Early Intervention of the District of Coimbra (PIIP) emerged in 1989, whose intervention was restricted in the beginning to the age group from 0 to 3 years old, was provided through supporting home visits and in the educational contexts where these children were on a daily basis. The PIIP of Coimbra aimed to integrate into practice all the theoretical principles underlying the practices of quality EI, and later recognized its pioneering in the country. The knowledge that this project contributed to the EI in Portugal allowed it to serve as a model for the first EI legislation in the country and simultaneously was in the genesis of the National Association of Early Intervention (ANIP) to support the development of good EI practices in the country (Pereira & Serrano, 2014).

In its number 6, JER No. 891/99 defines the three EI axes to be developed by the services, namely, family centered practices, teamwork and individual intervention plan. At the core of teamwork, it should be emphasized that services should be geared towards addressing the needs of families and children with special needs, enhancing their involvement, autonomy and empowerment in decision-making. Consequently, a large increase in specific support programs for children with developmental problems between the ages of 0 and 6 came through the "Being a Child" program in 1995. The influences that led to the construction of JER 891/99, of October 19, were based on US law in the area, namely Public Law No. 94-142 of 1975, Public Law 99-457 of 1986, and Public's Individuals with Disabilities Education Act (IDEA) Law 101-476 of 1990, which integrated responsibility for the health, education and social security sectors for EI support (Ruivo & Almeida, 2002).

#### 4.3.2 Is there any structured early intervention program in your country?

Ten years after the first legislative publication on EI in Portugal, Decree-Law no. 281/2009, of October 6, creates the SNIPI. This system aims to respond to children between 0 and 6 years of age who are at risk for changes or changes in body functions and structures, or who are at serious risk of developmental delay (Alves, 2009).

In the year 2013, the Ordinance No. 293/2013, of September 26, was created, which aims to expand the Support and Qualification Program of the National System of Early Intervention in Childhood (PAQSNIPI). This extension consists of the creation of Early Intervention Qualification Projects (PQIP) that aim in a multi-sectorial and integrated way, to reinforce the existing network of ELI constituted by Decree-Law no. 281/2009 of 6 of October, which created the SNIPI, and to qualify the intervention developed by the system, based on the needs that the government identified in the ELI.

Recently in 2017, the Resolution of the Assembly of the Republic No. 75/2017 recommends that the Government take the necessary measures, in particular hiring the professionals to meet the needs identified in the ELI and ensure adequate articulation of the entities involved. It aims to ensure the technical and material resources so that the ELI fulfill their duties.

#### 4.3.3 What are the procedural responsibilities of early intervention practitioners? (Reporting and registration)

The support of the SNIPI can be requested by different community services such as Hospitals, Health Centers, Social Security Services, Schools, Municipality and others as well as individuals and families by completing the SNIPI Reference Form or by contacting a ELI.

The eligibility criteria should be met, preferably by medical evaluation or by specialized medical reports submitted by the family. Children at risk of changes or changes in the body's structural functions and severe risk of developmental delays, which meet 4 or more biological and/or environmental risk factors, are eligible.

When the reported situation is not eligible for the SNIPI, the ELI should inform the family and the referral entity in person. If adequate, the ELI should refer the child to an appropriate service. The system also has a monitoring process for children who are not eligible but whom might have demonstrated signs of suspected developmental risk, and if so, they should be monitored by a period of time (every 3 to 6 months' period) to follow –up and make sure the child is not fall behind in terms of development.

Children who meet eligibility criteria for the ELI intervention are conducted to the Intake Team. The Intake Team is composed of one or more ELI members, defined by the team, according to the specific characteristics that each child eligible presents upon entry into the system. It is up to the Intake Team to collect information based on the observation and evaluation of the different contexts in which the child lives, as well as through contact with the family or legal caregivers of the child. To this end, the Intake Team should move in person to the context in which the child is. Generally, the Intake Team is responsible of preparing the following information:

- Characterization of the Child/Family;
- Routines-Based Interview (RBI);
- SATIRE;
- Ecomap;
- Declaration of Acceptance of the services signed by the family/caregivers of the child;
- Feedback information to the referral entity/individual.

All information collected by the Intake Team will be shared with the other ELI members in preparation of the intervention.

#### 4.3.4 What problems are you experiencing in practice?

- a) Lack of specific knowledge about early intervention body of scientific knowledge and state of the art recommended practices.
- b) Lack of professionals in the ELI.

#### 4.3.5 What are the solutions for these problems that you have encountered?

- a) Specialized centers of scientific knowledge in early intervention, namely the University of Minho, provide guidance and reflexive sessions about the practices to the members of the ELI in the northern region of the country. SNIPI's Technical Supervision Groups also provide guidance and support to the ELI members. The Technical Supervision Groups are constituted by professionals from the various areas of intervention of the Social Security Ministry, the Health Ministry and the Education Ministry with training and recognized experience in Early Childhood Intervention. The specific support functions of the Technical Supervision Groups to the ELI and the community are the following:
  - Analysis and verification of the application of the eligibility criteria of children referred for ELI;
  - Analysis and monitoring of the applicability of the concepts of surveillance and referral of situations referenced to other services;
  - Support and technical follow-up to the work carried out by the ELI, in particular with regard to monitoring the construction and organization of the Individual Processes of the Children covered, as well as evaluating the measures and actions expected in the PIIP, promoting their readjustment, whenever progress is insufficient;
  - Support and accompany the training of ELI professionals in the face of the conceptual model, which translates into a family and community-based intervention model based on family concerns and strengths and reinforcement of their competencies,
  - To support the ELI in the adoption of a transdisciplinary model of functioning, promoting a dynamic of sharing of theoretical and theoretical-practical knowledge among the various professionals;

- Support the ELI in articulation with the different entities with competence in matters of childhood and youth, in order to define procedures and signaling circuits,
- Promote with the ELI the diagnosis of community needs and resources, in order to stimulate formal and informal support networks.

b) The Portuguese Government aimed to reinforce the existing network of ELI through the Support and Qualification Program of the National System of Early Intervention in Childhood (PAQSNIP).

Recently the Resolution of the Assembly of the Republic No. 75/2017 also reinforced this need recommending the Government to do the following:

- 1 - Carry out the exact number of Local Intervention Teams in operation, identifying the number and type of professionals in each one, the municipalities to which they respond and the number of children and families accompanying them.
- 2 - Gather information at the national level on existing requests for early childhood intervention that have not responded in the past 12 months.
- 3 - Make a survey of the material and operational needs of each of the ELI in operation.
- 4 - Take the necessary measures, in particular the hiring of professionals, to fill the needs identified in the ELI, according to the survey carried out, and ensure the adequate articulation of the entities involved.
- 5 - Take the necessary measures to ensure the technical and material means for ELI to carry out their duties.

Currently the Social Security Institute also develops a Program for the Celebration or Extension of Cooperation Agreements for the Development of Social Responses (PROCOOP) that analyses the need for reinforcement or establishment of new ELI throughout the country.

#### 4.4 Physiotherapist as a member of the early intervention team in Portugal?

##### 4.4.1 Are there professional requirements for physiotherapists to take part in early intervention system?

To practice physical therapy, it is mandatory to have an undergraduate degree and a professional certificate approved by the responsible governmental entity. The undergraduate degree in physiotherapy lasts 4 years, with a total of 240 ECTS (European Credit Transfer and Accumulation System). Although undergraduate training addresses pediatrics topics, specific aspects of Early Intervention are only addressed in specialized graduate studies.

In the Portuguese context it is critical for an adequate practice in Early Intervention that the physiotherapists seek further studies after the completion of the undergraduate degree. Currently it is not mandatory to have specialized studies in Early Intervention in order to integrate a ELI, although it is highly recommended.

##### 4.4.2 Do you have pediatric rehabilitation, early intervention, typical and atypical motor development etc. lessons which can be elective or compulsory in physiotherapists' undergraduate, postgraduate, and life learning program education? If possible provide syllabus of lessons.

There are specific approaches in pediatric rehabilitation, typical and atypical motor development in the undergraduate bachelor in physiotherapy. Specific knowledge and practice in early intervention are only

focused in postgraduate studies such as the master degree in Special Education with specialization in Early Intervention as well as other post-graduate courses in Early Childhood Intervention.

*Some Examples:*

- Master Degree in Special Education with specialization in Early Intervention by the Institute of Education, University of Minho.

Year 1	ECTS
Inclusive Education and Special Needs	7.5
Research Methodology	7.5
Family-Centered Practices in Early Intervention	7.5
Option I <ul style="list-style-type: none"> <li>• Curriculum and Differentiation or</li> <li>• Communication Technologies</li> </ul>	7.5
The Child at Risk: Social and Psychopedagogical Perspectives	7.5
Clinical and Developmental Aspects of Children with NE	7.5
Stage in Early Intervention: A Case Study	7.5
Models and Specific Techniques for Early Intervention Evaluation	7.5
Year 2	
Dissertation	45
Seminar on Dissertation Support	15

- Post-graduation in Early Childhood Intervention by the ISPA - Instituto Universitário de Ciências Psicológicas, Sociais e da Vida (*University Institute of Psychological, Social and Life Sciences*).

Syllabus	ECTS
Development and learning: General	4,5
Atypical development and learning	6
Fundamentals and paradigms in Early Childhood Intervention	4,5
From planning to intervention in a family-centered perspective	7,5
Dimensions of functionality and participation: characterization and evaluation of the child and their contexts of development	7,5
Analysis of practices in Early Childhood Intervention	9
The team at Early Childhood Intervention and the community: models of work, collaboration and coordination of resources	4,5
Personal and professional development for a quality Early Childhood Intervention practice	4,5
Project	12

#### 4.4.3 How do you standardize the physiotherapy practices in early intervention?

Physiotherapy practices in early intervention are embedded in what is expected by the SNIPI from early intervention professionals. Support and Qualification Program of the National System of Early Intervention in Childhood (PAQSNIP) states that therapists should promote better functional performance, using specific therapeutic approaches, in order to facilitate greater participation in all contexts, activities and significant routines for the child and family.

The Portuguese legal framework for Early Intervention and the ELI internal regulations define the procedures of the professionals. The Decree-Law no. 281/2009 states that, Early Intervention means the integrated support package focusing on children and the family, including preventive and rehabilitative measures, in particular in education, health and social work. These measures, according to the needs of the families, are defined in an Individual Early Intervention Plan (PIIP) prepared by the ELI. The PIIP is both a document that allows the organization of all the information collected, the recording of all the aspects of the intervention as well as the process leading to its implementation. This document is elaborated according to the diagnosis of the situation, it involves the evaluation of the child in their contexts (family and others) and defines the measures and actions to be developed. The appropriate intervention presupposes the articulation between services and institutions, and is subscribed by the families.

Within the transdisciplinary model of work, professionals should foster the synergies of families as a team in:

- First contacts between the family and the Early Intervention service;
- Evaluation Planning;
- Evaluation of the Child;
- Identification of family concerns, priorities and resources;
- Developing objectives to meet the needs of the child and the family;
- Implementation of the PIIP;
- Formal and informal evaluation of PIIP and the PIIP process.

The physiotherapist should also be able to engage in a transdisciplinary model team. In the transdisciplinary model there are two fundamental principles: the perspective of child development as being integrated and interactive, and the care of children should be made available in their family context. Given that the family presents itself as the most influential element in the development of the child, this is perceived as the central aspect of the whole process, defining objectives and making decisions. All decisions related to evaluation, intervention plan and evaluation are defined by consensus, with the whole team. Although all team members share the development of the intervention plan, it is developed by the family and one of the elements of the team designated primary care provider (case mediator/coordinator).

Although there are similarities between the interdisciplinary approach and the transdisciplinary one, particularly when considering the permanent communication in which they are found, there are several differences in the roles played by the elements, in the evaluation and in the values underlying the model.

There is less rigidity in disciplinary boundaries in transdisciplinary teams, in which each member views the subject from a holistic perspective not being solely the responsibility of a discipline.

The transdisciplinary approach emphasizes mutual learning between its elements, practical application and education among professionals and a flexible exchange of roles among professionals. In the transdisciplinary model roles are not fixed, in which decisions are made by professionals who directly at a primary level. The boundaries between disciplines are deliberately to create an eclectic and flexible approach.

The transdisciplinary model promotes and empowers the child and family in their context, while at the same time strengthens the bonds of trust between the team members, who adopt in their practices the learning transmitted by colleagues from other disciplines. The family is considered the central element of the operation of the team, being considered an element of the same. It is parity at the role level aims to reinforce communication and collaboration standards among elements of the team, safeguarding the family's active role in decision-making, even when there is no unanimity between the views of the team members

## References

- Alves, M. M. (2009). *Intervenção Precoce e Educação Especial: Práticas de Intervenção Centradas na Família*. Viseu: Psicosoma.
- Carrilho, M.J. (2015). Children and Adolescents in Portugal. *Revista de Estudos Demográficos*, INE, 53 – 101. Retrieved :file:///C:/Users/Ana%20Serrano/Downloads/RED55\_art4%20(1).pdf
- INE (2015). Portugal in figures. Lisboa : INE Retrived: [https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine\\_publicacoes&PUBLICACOESpub\\_boui=251819980&PUBLICACOESmodo=2](https://www.ine.pt/xportal/xmain?xpid=INE&xpgid=ine_publicacoes&PUBLICACOESpub_boui=251819980&PUBLICACOESmodo=2)
- Pereira, A. P. S., & Serrano, A. M. (2014). Early intervention in Portugal: Study of professionals' perceptions. *Journal of Family Social Work*, 17(3), 263–282. doi:10.1080/10522158.2013.865426
- Ruivo, J. B. & Almeida, I. C. (2002). *Contributos para o estudo das práticas de intervenção precoce em Portugal*. Lisboa: Ministério da Educação.
- Serrano, A. M., Mas, J. M. Cañadas, M. & Giné, C. (2017). Family Systems and Family-Centered Intervention Practices in Portugal and Spain: Iberian Reflections on Early Childhood Intervention. In H. Sukkar, C. J. Dunst, & J. Kirkby (Eds). *Early Childhood Intervention: Working with families of young children with special needs* (pp.177-196). New York: Routledge.

## 5. General Overview of Early Intervention Implementations in Europe

In this report we summarise information from a report Eurllyaid published in 2015. In addition to the results of this survey we will include information we gathered from Spain (2017), Slovakia, Romania, Bulgaria, Poland and Hungary (2018). The 2018 survey included individual parents.

*“States Parties shall promote, in the spirit of international cooperation, the exchange of appropriate information in the field of preventive health care and of medical, psychological and functional treatment of disabled children, including dissemination of and access to information concerning methods of rehabilitation, education ... with the aim of enabling States Parties to improve their capabilities and skills and to widen their experience in these areas.”*

*Article 23 from the “Convention on the Rights of the Child” from 1989*

EURLY AID was started in 1989 at a conference in Rotterdam by a small and honorary group of scientists, parents and professionals. During the past 25 years the engagement of EURLY AID focused on the development and qualification of the professional work of Early Childhood Intervention (ECI) in Europe and neighbouring countries. The “Manifesto” was the first and most important document to define a standard and was published by the group, as it existed in those days.\*

In a report from 2015 we presented an overview of the conditions for the establishment of Early Childhood Intervention in 15 European countries based on the answers to a questionnaire Eurllyaid composed and send.

The background of the questions in the 2015 report are recommendations our former colleagues presented in 1993 within the Manifesto. We used seven of those recommendations to get answers about the actual situation in the different countries. (Belgium, Bulgaria, Croatia, Cyprus, Denmark, France, Great Britain, Germany, Greece, Holland, Norway, Portugal, Romania, Spain, Sweden, Parents’ associations: BOSK, Holland, BVKM, Germany)

We sent them to key respondents in the field of ECI such as Parents’ associations, professionals and academics. These persons have a critical insight concerning the conditions of their work. The collection of answers dates from 2014, about 20 years after the publication of the Manifesto. We received answers to the following seven questions together with some additional statements:

*“It is essential that children with disabilities receive help at an early stage. (...) At all times parents have the right to decide whether or not they will accept the help that is offered.”*

*“It is recommended that the government of each Member Country draw up its own policy plan for early intervention and put it into action by means of legislative and regulatory measures.”*

*“It is therefore (required) that each Member State provides the financial means required to carry out this policy plan.”*

*“Early recognition of developmental disabilities requires an adequate system of detection.”*

*“The diagnostic assessment must be aimed at the entire child in all (...) aspects, including his/her family and extended family.”*

*“A plan of action must be set up for each child individually and subsequently evaluated at fixed times. This plan of action is also geared to parents, the family and the broader network.”*

*“Parents must be actively involved in all phases of the intervention process.”*

Our survey, of course, did not present statistical results or official statements as such data (worldwide) are not available.

The 2015 report concentrated on three fields in order to summarize the implementation of ECI and the quality of professional work with children and their families. At the same time, it will indicate challenges for the future.

The 2018 survey concentrated on the current state on ECI in the 5 mentioned countries above.

### **1. Policy and financial resources:**

1.1 Does the country have a policy plan for early intervention and will put it into effect by means of legislative and regulatory measures?

1.2 Does the country provide the financial means required to carry out this policy plan?

### **2. Early detection and early support**

2.1 Does there exist an adequate system of early detection?

2.2 Do children with disabilities receive appropriate help at an early stage?

### **3. Individualization of the intervention and inclusion of the Family**

3.1 Is an individual plan of action a precondition as a distinctive mark of ECI?

3.2 Are parents or families actively involved in the plan of action and in all phases of the intervention process?

Each of the 15 countries country established a system to develop ECI under quite different conditions and as a specific system. Each country has its own cultural and social history to deal with the support of babies and young children with developmental problems, and their families. The awareness of the importance of ECI is obvious in all the answers we received from our colleagues in the 15 European countries. Of course, the conceptions of working in ECI are quite diverse, but in general, human rights are considered as a standard. The implementation of ECI is an on-going process, and we understand this report to be a reflection of the present situation that gives us reasons to improve the quality of ECI in favour of very young children and their families in the future.

## 5.1 Policy and Financial Resource

### DOES THE COUNTRY HAVE A POLICY PLAN FOR EARLY INTERVENTION AND WILL PUT IT INTO EFFECT BY MEANS OF LEGISLATIVE AND REGULATORY MEASURES?

- In 8 of the 15 countries a special law covers the right of Early Childhood Intervention (ECI) which guarantees the access, especially for children of less than 6 years of age, or it is focused on support for all children with special needs
- In some countries, a law does not specifically recognize ECI, but the system of social welfare covers the very different special needs of young children and their families by local authorities and at a good quality level.
- A few examples exist where the law integrates educational, health, and social care for a child and its family as an inclusive approach. Such a policy plan develops, and continues to develop, its quality in several steps of cooperation.

Even if a general law exists, in most of the countries regional authorities or communal authorities create their own guidelines (often in their financial interest to decrease the costs) which results in an extremely diverse quality of support, and the support of the families is often considered to be less important.

### DOES THE COUNTRY PROVIDE THE FINANCIAL MEANS REQUIRED TO CARRY OUT THIS POLICY PLAN?

- Big differences exist between the 15 countries. The financial resources differ from sufficient regulations to nearly zero. The distribution of the resources allotted by the country for dispersal by political units and local communities results in different budgets and very different quality standards for ECI.
- If financial support does exist, it often comes from different resources and very often without coordination. This leads to big differences between „poor“ and „rich“ communities. In some countries and in some cases, parents still have to pay for ECI.
- The amount of financial resources restricts home-based work, interdisciplinary work and coordination, and the number of children getting support. A well-organized interdisciplinary network or institution requires less financial support than the coordination of different special services at different locations.

## 5.2 Early Detection and Early Support

### DOES AN ADEQUATE SYSTEM EXIST FOR EARLY DETECTION?

- In almost all countries, there exist activities to develop or increase the information systems.
- The lack of cooperation between the different government or administrative departments and different welfare organizations complicates early detection.
- The basis for early detection of very young children is the medical system. There are programs developed especially for some groups of children such as for children with hearing impairments and premature babies.
- The chance to detect developmental problems is high, when the educators in a nursery or kindergarten are informed. –
- Professionals working with children have increasingly more responsibility for early identification of children's needs. This awareness is a very important challenge during professional training.

- There is a lack for professionals educated especially in child development. Services outside the Early Intervention system often are not openminded to ECI. They do not consider that ECI offers help and argue a system of control.
- In most countries, there exists a gap between very early detection within the medical system and the later detection when children are in a kindergarten setting, where there may be increased professional awareness.
- Early detection is lacking for children at risk, for children with no obvious pathology. Access is especially difficult for families living in poverty or who experience social problems.

#### **DO CHILDREN WITH DISABILITIES RECEIVE APPROPRIATE HELP AT AN EARLY STAGE?**

- In all European countries, early support exists in a great variety of concepts, organizations and accessibility. The systems vary from home-based, to centre-based, to specialized centres and to institutional care. In the majority of the countries, the services are free of charge and the access is easy. In some regions within several countries, ECI services are still lacking
- The variety of the different special needs of children and the availability of help from different disciplines very often is not coordinated and difficult for the parents to obtain.
- Since early support is depending on early detection of developmental problems there exists a functioning system for babies and very young children in most countries based on the medical system.
- In some countries, a paediatric nurse or midwife regularly visits the family. The chance to detect developmental problems is high when the child is in a nursery or kindergarten setting and the educators are informed.
- The choice to decide between different services exists only sporadically. Generally, there is only one ECI service in a (rural) community. In several countries, parents seem to be misinformed about existing resources, where to address their problems, or they do not even ask for help.
- Child neglect and abuse often correlate when parents do not have access to the appropriate information.
- In such situations of lacking information about existing resources, parents are not in a situation to make the right choices.
- Remarks of several countries stress the fact that parents can chose (if they have the choice) as long as their decision does not have a serious impact on the child's well-being.

### **5.3 Individualization of The Intervention and Inclusion of The Family**

#### **IS AN INDIVIDUAL PLAN OF ACTION A PRECONDITION FOR A DISTINCTIVE MARK OF ECI?**

- In some countries, the plan of action is "tailored" to the needs of the child including the family. The plan has to be discussed together with the parents and signed. The regular assessment needs time. The proposal for the frequency of new assessments is 6 months, 1 year, or following an actual situation.
- There are complaints about a considerable gap between the plan of action and its implementation in order to ensure a coherence because of the difficulties in cooperation between the different services and even the different professionals. - An inclusive approach prevents labelling on the one hand, but children's special needs could be in danger of being underestimated on the other hand. Standards of quality should be established and be compulsory for inclusive settings.

## ARE PARENTS OR FAMILIES ACTIVELY INVOLVED IN THE PLAN OF ACTION AND IN ALL PHASES OF THE INTERVENTION PROCESS?

- It is the right of the parents to be involved. There has to be respect for the level to which they want to be involved, together with the right to deny strategies of support that they do not consider being helpful.
- The child, its family and its environment are the initial point for a holistic intervention, based on a prior interdisciplinary assessment. (Environmental factors can be resources or barriers as well.) Families should participate in the identification of strengths, needs, and priorities. (Some systems involve them more than others.)
- Home visits are a very helpful opportunity to detect resources. The satisfaction of the parents is a decisive factor influencing the development of the child.
- Therapy and education cannot be efficient without the involvement of parents and adult persons living together with the child.
- There are big differences between the cultures in the European countries. There are traditional and more restrictive views of support, for instance institutional care on the one hand, and quite open family structures, which allow the discharge of responsibilities to different caregivers for the child on the other hand.
- Stress within the family often prevents parents from involvement. The necessary training to deal with difficult problems in the family is often lacking in professionals.
- The medical system is often predominant. Medical doctors and therapists continually have to be sensitized to interdisciplinary cooperation. The synthesis of different specialist is often difficult for a family to organize.

### 5.4 Summary

We dare to emphasize that in all of the countries the improvement of the organization and the quality is an on-going process of discussions and negotiations. This is the viewpoint we choose for the summation of the experiences in the 15 countries and for looking at how to implement appropriate conditions of ECI.

### 5.5 Legislation

The fact that in half of the countries the regulation of ECI has its basis in legislation is obviously a considerable step forward within the past 20 years, in allowing children the right to live and participate in their natural environment. At the same time, it stresses the necessity for the other countries to engage themselves in opening up the same rights for their children. A general countrywide control over the quality and effectiveness of ECI is lacking in almost all of the countries. The legal right of families to have access to ECI stimulates the experts working in this field to consider how to translate these rights into action. This is a crucial situation for the quality of the provided support as no compulsory regulations guarantee the financial requirements. This concerns the access for every family to at least the minimum of provided support. The qualification of the experts and the equipment of services are very different even in those countries where the general economic situation is favourable. All of it depends on provided, or lacking financial resources and their distribution; depends on a region with sufficient and

qualified services or services that exist only at great distances; depends on the level of expertise by the different professionals or on insufficient qualifications of the professionals. Even if a general law exists, in most of the countries regional authorities or communal authorities create their own guidelines, often in their own financial interest to decrease the costs. This is in contradiction to the equal rights of every European citizen that have to be respected in all 15 countries and in the other European countries as well.

### 5.6 Interdisciplinary Approach

A second step forward is the interdisciplinary approach of ECI. There exist examples of how the law integrates educational, health, psychological and social care for a child and its family. Such a policy plan has to develop its quality in several steps of cooperation and with the understanding that this is a work in progress, too. At the beginning services with the aim to support children with developmental problems were specialized services - specialized in the sense of classifying disabilities by diagnostics comparable to adult persons. Therefore, the authorities in charge of the different legal responsibilities independently from each other established different special medical services, different special educational services, and other services for young children with developmental problems. Investigations proved that therapy or stimulation based only on a biological diagnosis ignore the complexity of development. Experts planned ECI increasingly as a holistic approach for so-called “children with special needs”. Such an approach only works with the cooperation of experts from the medical, educational and psychosocial fields. We have to state that there exist many ECI services where interdisciplinary work is compulsory. By contrast, there exist services in several countries where specialization excludes interdisciplinary work. There the basis of the support is a medical view of the developmental needs of a child. The concept of prevention concerning children at risk or children with no obvious developmental problems is not in the focus of many services. Institutions outside the Early Intervention system often do not consider that ECI offers help and argue a system of control. The gap between specialized services in the medical field and the interdisciplinary services offered by ECI has to be an important issue in establishing cooperation for the future and promote the ECI work as an interdisciplinary necessity.

### 5.7 Family-Centered Practice

Finally, we can emphasize that the importance of the family in the course of the differentiation of ECI during the last 20 years is increasingly accepted as fundamental. The opening of the mind towards a holistic view of disability, considering more than the biological factors, embraces the embedding of the child in its family as being crucial. Professionals working in ECI generally acknowledge the right of the parents to be involved in the process of planning the support and translating it into action – often together with the whole family. Nevertheless, the quality of cooperation with the family is an issue of time and financial resources. There exists a general acceptance that the family must be involved. At this time, empowering the family is not always part of the program of support because administrators and parents regard early intervention as focused on the child. This field needs to be “enlightened”. There are big differences in the existing cultures of the European countries, as a traditional context leads to institutional care on the one hand, and very open structures where the charge of responsibilities towards children changes within families, caregivers or one-parent families on the other hand. Including

families in the support for children with developmental problems is irrefutable as a basis of ECI work in the 21st century. The flexibility of the ECI concepts should be open in financial and intercultural respects to provide the right kind of support even while considering the different necessities and circumstances

In addition to the above (abstracted from the Eurlyaid report, performed and published in 2015), we quote from a recent summary report we performed and coordinated- within the Agora project – in which Eurlyaid is involved as partner. In this project the following 5 countries participate: Hungary, Romania, Slovakia, Poland and Bulgaria. Due to the fact both reports are from a wider perspective and include multiple countries other ways of collecting the information were used than the overall format within the VET project for the country reports.

The entire summary report, and the country reports it is based on, will be available in due time on our website ( [www.eurlyaid.eu](http://www.eurlyaid.eu)) and the project website.

The country reports were based on the “The Developmental Systems Model” introduced by M. Guralnick (2001, 2005). This model encompasses and connects the wide range of strategies offered to young children with disabilities or at risk of developmental delays or disabilities and to their families and offers a framework for the development of more effective policies and strategies in the field of Early Intervention.

Because of the length of the entire summary report we only quote the main summaries, challenges and overall conclusions.

### **Screening and referral**

The main goal of the screening program and referral is early detection and identification of children that have developmental difficulties. It is an entrance point for children and families that can be initiated by parents and professionals in response to their concerns about the child’s development.

**Main challenges:** As mentioned above, effective and efficient Screening and Referral programs require a high level of cooperation among the sectors and parties involved. However, despite some positive developments, all countries report that there are no clearly regulated pathways in the screening and referral process. The cross-sectoral coordination is either in the process of being established, or, as is the case of Romania and Slovakia, is still absent and the screening procedures are organized by sector. This situation is exacerbated by the shortage of medical personnel as well as lack of information and public awareness about early intervention. As a result, not all children may be included in the screening, especially children at risk. Parents are not always aware which organization they should contact for screening or self-referral; and there are no comprehensive statistics as to how many children need support and do not receive it.

### **Monitoring**

According to the DSM, for children who do not meet screening criteria for referral, monitoring and surveillance remains of great importance, especially, if the children maintain a risk status (e.g., premature children) or their parents have any concerns with regard to their development.

**Main challenges:** Only in Bulgaria the monitoring component exists in the Social Protection sector, whereas in Hungary and Poland it is limited to the Healthcare and Education sectors, which may leave psychosocial problems and risk factors unnoticed. The cross-sectoral coordination of the monitoring is still lacking, and individualized monitoring protocols are yet to be developed in Hungary, Poland, Romania and Slovakia. Lack of qualified specialists who are trained to perform the monitoring presents another challenge. Moreover, according to the country reports, the families are often poorly informed about the monitoring procedures in different sectors, and are not aware in which cases and under what conditions they can apply for monitoring. Slovakia points out that one of the main challenges in the development in this process is to introduce the monitoring in the quality standards of the Healthcare sector and start implementing it.

### **Point of Access**

Point of access (PA) to early intervention system comes to play when a concern about development reaches certain criterion (including parental concerns resulting in self-referral) or risks to development are high enough. It represents a location or setting where the process of gathering, integrating, and coordinating information occurs, and families are introduced to the possible services and forms of support that the system can provide. The way communities address PA serves as an important index of the overall level of integration and coordination of the system of services.

In larger communities there should be multiple Points of Access to ensure the availability and proximity of services.

**Main challenges:** This component is one of the least developed in the five countries with the exception of Hungary and requires special attention. Among the main challenges, lack of trained personnel, resources and cross-sectoral cooperation can be mentioned. If PA exist, they are not evenly distributed and are lacking in rural areas. According to the country reports, the unified record-keeping system and database are yet to be created in all five countries, except for Hungary. The families usually lack the information about the PAs or their equivalents.

### **Comprehensive Interdisciplinary Assessment**

This is the essential part of the DSM that facilitates a subsequent treatment plan.

**Main challenges:** According to the country reports, interdisciplinary teams within different sectors focus on different aspects of the assessment: either health (traditionally by the Healthcare sector), or developmental profile of the child, or family functioning. The latter is usually done within Social Protection sector in case of families with psychosocial problems which hampers comprehensive assessment and the subsequent stages in service provision. In addition, lack of cooperation between the

sectors can lead to the unnecessary duplication of assessment procedures performed within each sector which creates unnecessary confusion and loss of valuable for the child and family time and resources. Furthermore, Hungary as well as Poland report that parents are insufficiently involved and informed about the assessment.

### **Eligibility for the ECI system**

Eligibility decisions are usually based on pre-determined criteria that facilitate referrals of children to early intervention program (children with delays or disabilities) or to the preventive intervention program (based on biological and environmental risk factors).

Importantly, children who do not meet eligibility criteria should remain in the system through the Monitoring and Surveillance, especially if the parents are concerned about their development. Eligibility criteria should be consistent across different organizations, sectors and counties.

**Main challenges:** The fact that eligibility criteria for children at risk have not been established yet, means that many young children and their families may not receive the necessary support on time, important preventive opportunities may be lost or with time become less effective, while children may not receive vital chances for the best start in their lives.

Furthermore, at the moment in all countries each sector applies its own eligibility criteria and they are not consistent across the organizations and sectors. As a result, the parents report not being informed or being confused about the criteria and the necessary steps to be admitted to the ECI. They are often overwhelmed with the bureaucratic and sometimes redundant or confusing rules and requirements from the different sectors and organizations.

### **Evaluation of potential stress factors for families**

Assessment of stressors is a central component of the DSM that helps to modify and refine the intervention program after the entry of families to the (preliminary) EI program. This component is voluntary in nature and reflects the overarching developmental framework, namely:

- the focus on families;
- the highly individualized nature of the Comprehensive Intervention Program;
- sensitive to cultural differences in the formation of parent—professional partnerships.

**Main challenges:** Although there is a growing realization of the importance of this component, according to the country reports, the assessment of stressors is often focused on the stressors associated with the child and not with the family. In addition, if the assessment of stressors is undertaken, it does not happen in a systematic way, and is usually based on clinical judgment of experienced professionals in different sectors and not on the relevant inter-disciplinary measures and assessment tools. Furthermore, the latter are often not readily available.

Although in Slovakia ECI centres functioning within the social protection sectors have such tools at their disposal and apply them in practice, in Healthcare and Educational sector this component remains neglected.

### **Development and implementation of individualized service plan**

In order to minimize the stress on family patterns of interaction a plan specifying resource supports, social supports, and information and services tailored to the stressors and needs identified in the previous component of the DSM must be developed. The core principles of developmental framework, inclusion, and integration and coordination are of vital importance for this component.

**Main challenges:** Lack of well-established assessment of stressors component, lack of cross-sectoral cooperation and information for the parents, who, as country reports reveal, are often unaware about the existence of the individualized service plan, impede the realization of this component in all five countries.

### **Monitoring and outcome evaluation**

Monitoring and evaluation procedures help to ensure the quality of ECI services. It must occur at following levels:

- Evaluation of progress toward goals and objectives;
- Reassessment of stressors;
- Decisions as to when comprehensive interdisciplinary assessments or reassessments are needed;
- Assessment of the functioning of the system and integration of different components;
- Evaluation of the realization of the core and related principles for each of the systems components.

Parent reports, self- evaluation protocols for administrators and early intervention professionals, or external evaluations are relevant strategies for this component of the DSMECI.

**Main challenges:** According to the country reports, there is an urgent need in the ECI standards of services, quality measures and regular monitoring and outcome evaluations. Currently, central data base and the communication of the core information with the central database is lacking in all five countries. Also, the sampling procedures involving independent evaluations are still to be developed and introduced in the countries under consideration. Although some countries manage to perform the monitoring and outcome evaluation, it appears to be mainly focused on the child, there is less or no attention for parent and professional satisfaction and efficiency of the provided interventions and services and system in general which is not in line with the DSMECI.

### **Transition planning**

As the final component of the DSM model it helps to ensure continuity and creates as smooth a transition as possible. Transition can take place at many points and have various forms, e.g. from hospital

to home, from infant—toddler to preschool programs, or when the transition is made from preschool to kindergarten. For children with special needs and their parents transition can be very challenging and stressful

**Main challenges:** Despite existing efforts around transition planning, both in Hungary and Poland parents are often left to their own devices when it comes down to transition planning and the choice of institution to which they apply for support. Slovakia reports that even when transition planning is undertaken, children with disabilities have very limited choices. The main challenge for all five countries is cross-sectoral cooperation and involvement of the private service providers in all DSM components, including transition planning, to ensure the quality and equity of ECI services.

### **Policy and legislation**

By ratifying the UN Convention on the Rights of the Child and the UN Convention on the Rights of Persons with Disabilities all five countries have established the legal foundation for the development of ECI services and systems and introduction of the DSM model components in line with the principles and provisions of these international treaties. The implementation and enforcement of these principles at national, regional and local levels, is now in progress and requires the development of:

- National standards for ECI service provision;
- Regulatory mechanisms at national (cross-sectoral) level;
- Relevant sectoral (ministerial) laws, regulations and protocols;
- Regulatory mechanisms at local/regional level.

**Main challenges:** Although formally Bulgaria appears to be rather advanced in the implementation of the regulatory basis for ECI as a result of the country's current unfavourable economic situation, the number of ECI services is not sufficient. This is despite the strong motivation of various institutions, civil society organizations, and individuals. In most cases, early intervention services are provided within projects, which does not guarantee their sustainability and, according to the country report, parents are often uncertain about services that they receive and their children's development. In Slovakia the majority of the ECI service providers belong to the private sector where quality standards are not implemented, the same situation applies to the services within Health and Educational sector. Finally, Healthcare sector in Hungary, Poland, Romania, and Slovakia remains uninvolved in the development of legislation and regulatory mechanisms of the ECI service provision, which, in turn, keeps behind the development of the comprehensive cross-sectoral ECI system.

### **Funding and financial resources**

One of the basic principles of ECI is access to affordable quality services allowing children with disabilities and their families to overcome financial barriers that can prevent them from getting timely necessary support. Adequate financing of ECI services is essential for the implementation of legal obligations discussed above as well as sustainability of existing ECI services. In order to continue to create a network of accessible and affordable ECI services well developed mechanism of ECI funding, should be in place.

**Main challenges:** Country reports demonstrate that ECI remains an underappreciated and underfunded area. Apart from financial and economic hardships, decentralization and other reforms, an important reason for reduced funding of the ECI, according to the Polish report, stems from the lack of research data and knowledge and awareness of the policy and decision makers of the fact that investing in the earliest years leads to some of the highest rates of return to families, societies and countries.

While services in the five countries functioning within Healthcare, Educational and Social Policy sectors are in most cases financed by the governments, for NGOs providing ECI lack of financial mechanisms and allocation of funds inevitably leads to the lack of stability and sustainability of their services. They often have to charge families for their services which makes them less affordable, and sometimes even burdensome for the family budgets. At the same time, it is the NGO service providers who are usually more flexible in following the needs of the child and families and quick and proactive when it comes down to the introduction of new innovative programs and practices.

### **Personnel development**

A comprehensive system of ECI personnel development is an important and integral quality indicator of an early childhood service system. Children with disabilities and their families make optimal progress when services are delivered consistently and at a high-quality level across different sectors, service providers, teams and professional disciplines. To ensure high quality learning necessary resources and opportunities should be developed and provided through coordinated pre-service and in-service training programs, supervisions and certification of the ECI specialists, as well as train-the-trainer programs.

### **Conclusions**

This report presents the analysis of the current situation with regard to the ECI systems and services in Bulgaria, Hungary, Poland, Romania, and Slovakia, based on the Developmental Systems Approach to Early Childhood Intervention by Guralnick, M., (2001, 2005, 2011) used as a framework for the development of ECI policies and services. Analysis of the data presented in the country reports allows the following conclusions to be drawn:

- In all five countries the services in different sectors continue to be mainly focused on a child rather than families and their resources and stressors, as DSMECI emphasizes. Therefore, the first core principle, i.e., developmental framework, is only partially realized in the existing systems of services. However, country reports also demonstrate an emerging understanding and appreciation of the role of families in the development of young children, as well as the efforts to address the needs of the families and involve them at different stages of ECI service delivery.
- As to the second core principle of the DSMECI, related to the integration of different services and administrative structures and institutions, involved in the service provision at different levels, its realization remains likewise rather problematic in all five countries. The lack of cross-sectoral cooperation and coordination, different ministerial laws and normative regulations

within Healthcare, Education and Social Protection sectors, lack of communication between the sectors and agencies negatively affect the implementation of all components of the DSMECI.

- The realization of the third core principle of inclusion and provision of services in natural environments as well as maximization of the participation of children and families in typical community activities, despite some positive developments, also remains a challenge for all five countries due to the co-existence of the inherited from the old system and inspired by the medical model institution-based approach and DSMECI approach. Other challenges are limited resources; gaps in service availability, accessibility, quality, and equity based on family income, disability and location; and mentioned above lack of information and coordination between the agencies that limit the possibilities and hamper the inclusion of young children with special needs and their families.
- As far as the specific components of the DSMECI are concerned, according to the country reports, such components as screening and referral and interdisciplinary assessment appear to be most advanced, which may be related to a certain overlap between the traditional medical approach and DSMECI approach with regard to these activities.
- The least developed components of the DSMECI are the points of access, assessment of stressors (implemented only in Bulgaria), monitoring and outcome evaluation and transition Planning.
- The development of different aspects of the DSMECI components and their implementation varies substantially within the countries, and since they are closely interrelated it affects the implementation and functioning of the ECI system as a whole.
- Among **the main challenges** in the implementation of the DSMECI identified by the countries, the following factors are mentioned:
  - lack of comprehensive overarching regulatory framework;
  - limited financial resources, especially what concerns NGO service providers;
  - limited opportunities for personnel development;
  - limited or absent cross-sectoral cooperation;
  - lack of data and information;
  - lack of professional and public awareness about ECI.
- A serious concern is that children at risk of developmental delays or disabilities and their families are poorly supported by the existing services which means that many young children and their families may not get the necessary support on time and important preventive opportunities may be lost or with time become less effective.
- Each country offers some positive examples and solutions that are described in the report and can be seen and disseminated as good ECI practices. Information from Romania that would allow to identify good examples and practices was not available.

### **Limitations**

The situation analysis presented in this report is exploratory in its nature; it was not intended to offer final and conclusive solutions to existing problems in the field of ECI in the five countries. The main limitation of this study is the selection of the participants in the qualitative component of the country

researches and insufficient data on some aspects of the DSMECI components. Therefore, further research is needed with more rigorous design, instruments, sampling methodology and data collection method.

#### References:

[http://www.eurlyaid.eu/download/eurlyaid\\_documentation/eaei\\_manifesto\\_eng.pdf](http://www.eurlyaid.eu/download/eurlyaid_documentation/eaei_manifesto_eng.pdf)

[http://www.eurlyaid.eu/wp-content/uploads/2016/05/eaei\\_eci\\_development\\_eng.pdf](http://www.eurlyaid.eu/wp-content/uploads/2016/05/eaei_eci_development_eng.pdf)

[http://www.eurlyaid.eu/wp-content/uploads/2016/05/eaei\\_assessment\\_eng.pdf](http://www.eurlyaid.eu/wp-content/uploads/2016/05/eaei_assessment_eng.pdf)

[https://www.european-agency.org/sites/default/files/early-childhood-intervention-analysis-of-situations-in-europe-key-aspects-and-recommendations\\_eci\\_en.pdf](https://www.european-agency.org/sites/default/files/early-childhood-intervention-analysis-of-situations-in-europe-key-aspects-and-recommendations_eci_en.pdf)

[http://depts.washington.edu/chdd/guralnick/pdfs/overview\\_dev\\_systems.pdf](http://depts.washington.edu/chdd/guralnick/pdfs/overview_dev_systems.pdf)