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1 Introduction

November 17, International Day of the Premature Child

Babies who are born before 37 weeks of pregnancy are called premature. This means that the baby is born prematurely more than 3 weeks, as a pregnancy normally lasts 40 weeks. We distinguish premature born children on the basis of the duration of the pregnancy.

The gestational age also determines the length of stay in the hospital or the possible consequences for the development of the baby.

The majority of premature children are born between 32 and 37 weeks. Children born for a gestational age of 28 weeks are called extremely premature. Children born after a gestational age between 34 and 37 weeks are called late premature.

75% of the premature births are caused by premature labour or by the spontaneous breaking of the membranes. In 25% of premature births, this premature birth is the physician's decision due to problems with the health of the mother or child.

Newborns with a birth weight that is not in agreement with the gestational age (too low) are called dysmatures.

Medical knowledge and care have improved enormously in recent years. Nevertheless, there is a lower limit for the treatment of premature children. The risk of death and physical and mental disabilities increases as the gestational age and / or birth weight is lower. The lower limit for treatment

in Flanders, it is generally set at 24 weeks gestation in consultation. The decision to treat or not treat a child born between the ages of 24 and 26 is taken jointly by the parents, the paediatrician and the gynaecologist. The therapy and possible consequences for the baby and mother, in the short and long term, are taken into consideration.

For children younger than 24 weeks of gestational age, intensive treatment is not started because the chance of survival is very small and the risk of serious limitations in later life is high.

Premature birth occurs after the early start of the birth. A number of risk factors increase the chance of preterm birth:

- Pre-history of delivery for the 37th week of pregnancy
- Vaginal blood loss
- Abnormalities at the uterus
- Trauma or surgery on the cervix
- Fertility treatment
- Age of the pregnant under 18 or older than 40 years
- Multiple pregnancy
- Low weight of the mother
- Low socio-economic status

In addition, the chance of premature birth increases due to:

- Anemia
- Active and / or passive smoking during pregnancy: harmful substances in cigarettes cause a reduced circulation in the placenta and a reduced oxygen supply to the baby.
- Lack of healthy food: what you eat and drink during your pregnancy has a major influence on the course of your pregnancy and the development of your child.

- Poor oral hygiene: during pregnancy, the gums become more sensitive and teeth are prone to deterioration. In tooth decay, bacteria can spread through the body through the mouth and adversely affect the development of your child. A gum disease increases the chance of preterm birth.

Important!: Since the borders in Europe are gone, the number of non-Dutch speaking parents in neonatal departments has risen sharply. A brochure for non-native speakers, with a lot of visual material and accompanying text, is needed to give the parents the necessary basic information when they arrive at the department.

2 National reports

2.1 Population and prevalence of births with congenital anomalies and premature babies

2.1.1 Flanders (Belgium)

Inhabitants Flemish region: 6,516 million (1 January 2016)

Premature birth

Approximately 7% of mothers give birth too early each year. Taking into account twins and multiple births, this corresponds to more than 8% of the children. Concretely, this means that 1 to 2 children were born prematurely in every nursery class. A premature birth is also a traumatic event that has a major impact on the whole family: the child, the mother and the father. The child is not ready to function independently outside the mother's womb, but the parents are often not ready for the arrival of their child and still have a long way to go in their parenting sense.

Prevalence: In Flanders 1 in 15 babies are born before the 37th pregnancy week (3 weeks early) and 1 in 100 before the 32nd week of pregnancy (8 weeks early).

In 2013, 8.3% of the children were born prematurely.

Congenital abnormalities

Prenatal

Prenatal testing can in some cases give the expectant parents a definitive answer about the presence or absence of a certain condition in their baby. However, the application of the current possibilities of prenatal screening and diagnostics in clinical practice raises a delicate ethical question that is coloured both historically, socially and philosophically. Several factors determine how today the ethical questions surrounding prenatal diagnosis are formulated and answered: the existing medical possibilities, the organization of prenatal health care in Flanders, the place of the child in our society, the importance of health in a person's life, philosophical convictions, the pluralistic social context, and son.

Prenatal examination (chorionic villus testing, amniocentesis, neck fold measurement, ...) aims to investigate whether a deviation can be established in the foetus. Not every pregnant woman is immediately eligible for a diagnostic, often invasive form of prenatal diagnosis. There must be a risk situation that is indicative of this research. The following indications are taken into account[1]:

- high risk for numerical chromosomal abnormalities via age of the mother and first trimester risk calculation (fold of the neck, biochemistry);
- previous child with numerical chromosome abnormality;
- carrier structural chromosome error;
- presence of mono-inherited disorders;
- ultrasound abnormalities.

Methods:

Methods of prenatal screening:

- Combined neck fold measurement and biochemistry
- Ultrasound

Diagnostic methods

- The triple test
- Flocculation test or chorion biopsy
- Amniocentesis
- Umbilical cord puncture
- Pre-implantation Genetic Diagnosis (PGD)
- Foetal cells / foetal DNA in maternal plasma (biochemistry)

In Flanders, the medical supervision of the pregnancy is done by gynaecologists, general practitioners and midwives. Gynaecologists are by far the most important actors. According to Kind & Gezin (K & G), 95.3% of pregnancies were monitored by the gynaecologist in 2010 and 4% by gynaecologist and general practitioner.[2,3]

The gynaecologist in Flanders is the first point of contact for everything concerning prenatal care, pregnancy and childbirth[4]. There are gynaecologists with special skills in prenatal diagnosis in Flanders, guidelines on specific training or their powers were not found. A declining trend of pregnancy guidance by general practitioners is observed. By following fewer and fewer pregnant women, GPs lose their routine and knowledge about this. To improve their knowledge, a specific interest on their part is required, because the training and meeting obstetrics are limited. It is recommended that general practitioners who do pregnancy monitoring make this known and cooperate with

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[1] Witters, I. & J.-P. Fryno s, Prenatal Diagnosis. Clinical Aspects. In C. Gastmano s (ed.), Between Technology and Humanity. The Impact of Technology on Health Care Ethics, Leuven University Press, Leuven, 2002, 69-79.

[2] Kind en Gezin: Het kind in Vlaanderen. Online 2010. Opgehaald op 20 november 2014, van http://www.kindengezin.be/brochures/KindinVlaanderen/index.html#/138/

[3] Hoogewys A, De Grave H, Van Ham P, Van de Velde G. Koning Boudewijno stichting: Perinatale ondersteuning van kano sarme gezinnen: wat er is en wat er nodig is. Online 2013. Opgehaald op 10 oktober 2014, van http://www.kbs-frb.be/uploadedFiles/2012-KBSFRB/05%29_Pictures,_documents_and_external_sites/09%29_Publications/PUB2013_3168_Prenataal.pdf

[4] Hoogewys A, De Grave H, Van Ham P, Van de Velde G. Koning Boudewijno stichting: Perinatale ondersteuning van kano sarme gezinnen: wat er is en wat er nodig is. Online 2013. Opgehaald op 10 oktober 2014, van http://www.kbs-frb.be/uploadedFiles/2012-KBSFRB/05%29_Pictures,_documents_and_external_sites/09%29_Publications/PUB2013_3168_Prenataal.pdf

gynaecologists for example for ultrasound scans and timely referral[5]. For Belgian midwives, a clear professional profile was drawn up in 2006 [6]. The midwife is trained to accompany the normal pregnancy, normal parturition and normal childbirth independently, but unlike some other countries, the midwife in Flanders has a limited role. She mainly works in the second line in the assistant role in the delivery and maternity ward and the number of maternity follow-ups by independent midwives is low[7,8]. A quantitative descriptive study, however, showed that 88% of pregnant women in Flanders see extra talks with a midwife during their pregnancy. This mainly tobtain additional information, advice and answers to questions[9]. A separate professional group of sonographers does not exist in Belgium. Ultrasonography is mainly performed by gynaecologists. Some midwives are allowed to perform ultrasound scans, but the basic training for midwife is insufficient for this.

Data on birth defects in all children in Flanders are alone available from the obstetric registration (SPE). In 2011, one or more major deviations were observed in 1% of births in the perinatal period. This is a slight increase compared to 2010 (+ 0.15%).

Below table[10] gives a detailed picture of the prevalence of major congenital abnormalities in children born in 2011 (when interpreting this figure, account must be taken of the fact that after prenatal screening, in a number of cases there is an abortion). This shows that the deviation cleft lip / palate occurs most frequently (13.2 per 10 000 births), followed by the abnormality ventricular septal defect.

Congenital major defects	**# 2009**	**Per 10 000 pregnancies**	**# 2010**	**Per 10 000 pregnancies**	**# 2011**	**Per 10 000 pregnancies**
Anencephaly	5	0,7	7	1,0	6	0,9
Spina bifida	20	2,9	15	2,1	20	2,9
Hydrocephaly	24	3,5	23	3,3	29	4,2
Transposition large vessels	19	2,8	34	4,9	31	4,5
Deviation long	12	1,7	10	1,4	6	0,9
Atresia small intestine	8	1,2	15	2,1	17	2,4
Kidney agenesis	13	1,9	10	1,4	25	3,6

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[5] Peeters S, Theuwis C. Optimaliseren van zwangerschapsbegeleiding in de huisartsenpraktijk: een prospectief kwalitatief onderzoek. Masterproef in het kader van de opleiding tot arts, Universiteit Antwerpen. 2012-2013; 2-69.

[6] Nationale Raad voor de Vroedvrouwen. Beroepsprofiel van de Belgische vroedvrouw. Online 2006. Opgehaald op 2 mei 2018, van http://www.vlov.be/sites/default/files/Beroepsprofiel%202006.pdf

[7] Hoogewys A, De Grave H, Van Ham P, Van de Velde G. Koning Boudewijno stichting: Perinatale ondersteuning van kano sarme gezinnen: wat er is en wat er nodig is. Online 2013. Opgehaald op 10 oktober 2014, van http://www.kbs-frb.be/uploadedFiles/2012-KBSFRB/05%29_Pictures,_documents_and_external_sites/09%29_Publications/PUB2013_3168_Prenataal.pdf

[8] Nationale Raad voor de Vroedvrouwen. Beroepsprofiel van de Belgische vroedvrouw. Online 2006. Opgehaald op 2 mei 2018, van http://www.vlov.be/sites/default/files/Beroepsprofiel%202006.pdf

[9] Luyten H. De vroedvrouw en de gynaecoloog samen op consultatie: verloren moeite of de moeite waard? VLOV. 2000;3: 82-87.

[10] Geregistreerde aangeboren majeure afwijkingen (perinatale periode) in Vlaanderen: aantal en per 10 000 geboorten Bron: H. Cammu, E. MartEns, G. MartEns, C. Van Mol, Y. Jacquemyn, Perinatale activiteiten in Vlaanderen 2011. SPE, Brussel. Majeure afwijkingen vasto gesteld bij de geboorten in kraamklinieken (³ 500 g). Bij een kind kan meer dan 1 afwijking worden vasto gesteld.

Congenital major defects	# 2009	Per 10 000 pregnancies	# 2010	Per 10 000 pregnancies	# 2011	Per 10 000 pregnancies
Craniosynostosis	1	0,1	5	0,7	15	2,2
Turner syndrome	5	0,7	1	0,1	4	0,6
Obstruction renal pelvis and ureter	35	5,1	31	4,4	47	6,8
Cleft lip / palate	87	12,7	120	17,2	92	13,2
Anal imperfection	15	2,2	7	1,0	9	1,3
Reduction of limbs	28	4,1	31	4,4	26	3,7
Tetralogy of Fallot	20	2,9	13	1,9	23	3,3
Oesophageal atresia	19	2,8	11	1,6	16	2,3
Atresia anus	10	1,5	9	1,3	21	3,0
Twin-to-twin transfusion syndrome	2	0,3	1	0,1	11	1,6
Skeletal dysplasia / dwarfism	15	2,2	23	3,3	18	2,6
Hydrops fetalis	10	1,5	9	1,3	8	1,1
Poly / multichystic kidney dysplasia	17	2,5	19	2,7	22	3,2
Hernia diaphragmatics	16	2,3	22	3,1	29	4,2
Omfalocele	9	1,3	17	2,4	7	1,0
Gastroschisis	15	2,2	9	1,3	22	3,2
Ventricular septal defect	81	11,8	63	9,0	82	11,8
Atresia bile ducts	3	0,4	2	0,3	3	0,4
Hypospadias	67	9,7	71	10,2	80	11,5
Cystic hygroma	1	0,1	4	0,6	2	0,3
Trisomy 21	41	6,0	46	6,6	48	6,9
Trisomy 18	5	0,7	4	0,6	9	1,3
Trisomy 13	4	0,6	6	0,9	7	1,0
Other heart defects	65	9,5	54	7,7	76	10,9
Total children with one or more congenital major defects	**565**	**82,2**	**595**	**85,1**	**677**	**97,3**

Natal

As a result of an unfavourable position or presentation, various complications can occur for the baby, such as:

- Foetal distress is a situation in which your baby does not get enough oxygen by, for example, defecation of your baby in the amniotic fluid, a deviating heart rhythm or a placenta that does not work. The baby's heart rhythm should therefore always be closely monitored and, if necessary, an artificial redemption or caesarean section should be performed.
- An abnormal birth position, for example when your baby is facing the abdomen, will be relieved if necessary with art redemption or caesarean section,

- A forehead or facial position (respectively the forehead is bent forward and the neck is bent backwards) do not usually ask for intervention because your baby often automatically turns into the right position.
- Breech presentation means that your baby is lying backwards, swith the buttocks first. Here, in the worst case scenario, the baby's head can get stuck with nerve or brain damage (due to lack of oxygen) or even death as a result. Sometimes a doctor can, in the last weeks of pregnancy, turn your baby by pushing your belly. If this is not possible then there is usually opted for a caesarean section so that the risks for the baby remain limited.
- Shoulder Dystocia means that the head of your baby is already born but a shoulder remains stuck behind the pubic bone of the expectant mother. As a result, the child cannot breathe and an artificial redemption or caesarean section must be performed. Most cases of shoulder dystocia occur in relatively large babies.
- Depletion of the umbilical cord is a situation where the umbilical cord comes out even before the baby is born. The umbilical cord may get stuck with an oxygen deficiency for the baby as a result. A caesarean section will have to be performed to bring the baby healthy in the world.
- Umbilical cord entwined the baby's neck is a situation that occurs in about a quarter of the births. Fortunately, this does not have to have any harmful consequences for your baby because a doctor can feel the position of the umbilical cord during delivery and slide it back over the baby's head.

A lack of oxygen in the baby during birth can also be the cause of certain birth defects or disabilities (e.g. Cerebral Palsy). Because, for example, a non-functioning placenta, or if the umbilical cord is wrapped around the baby's neck, the little brains may temporarily not have received enough oxygen.

Perinatal mortality in Flanders was 5.5 ‰ in 2016: 81.0% foetal and 19.0% early neonatal. It concerns newborns with a birth weight of 500 grams or more. If we only consider the babies whose birth weight is 1 000 grams or more, the perinatal mortality decreases to 3.4 ‰, of which 81.4% foetal and 18.6% early neonatal.
The causes of death of the newborn remain unchanged. At 21.8% the cause is unknown. This means that in more than one third of the cases of perinatal mortality (21.8% + 13.2% = 35.0%) it is not known why the child has died. Among the live-born, the main cause of death is still low birth weight / preterm birth.[11]

Post natal

On the basis of the Flemish Government Decree of 6 May 1997 concerning centres for metabolic disorders, all newborn babies in Flanders can be tested for 11 congenital disorders between the 3rd and 5th day after birth (this is not mandatory, but is a free initiative of the Flemish Population Screening of Congenital Diseases). This is done through a blood test. The costs of the research are paid by the Flemish government. The research is free for the parents themselves.

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[11] Vzw Studiecentrum voor Perinatale Epidemiologie (SPE), PERINATALE ACTIVITEITEN IN VLAANDEREN 2016, Redactie: R. Devlieger, E. MartEns, G. MartEns, C. Van Mol, H. Cammu, https://www.zorg-en-gezondheid.be/sites/default/files/atoms/files/SPE-jaarverslag%202016.pdf

A few drops of blood are collected on a card with filter paper (blood card) through a puncture in the back of the baby's hand. The blood tickets are sent for research tone of the Flemish centres for detection of congenital metabolic disorders. A modified approach is used for prematures and sick newborns.

The result of the blood test is only reported to the parents if it is abnormal. In that case, the treating physician of the newborns is informed. Additional studies will be carried out in consultation with the parents. As soon as the diagnosis is known, appropriate treatment can start.

The eleven diseases can be divided according to cause in four large groups:

- disorders in the metabolism of building blocks of proteino s (Phenylketonuria (PKU) or Hyperphenylalaninaemia (PKU), Maple Syrup Urinary Disease (MSUD), Methylmalonacidemia (MMA) / Propionic Disease (PA), Isovaleraemia (IVA), Glutaric Acidemia Type 1 (GA1)) ;
- fatty acid burning disorders (Medium-chain ACYL-COA Dehydrogenase Deficiency (MCADD), Multiple ACYL-COA Dehydrogenase Deficiency (MADD));
- disorders in the reuse of vitamin biotin (Biotinidase Deficiency (LMCD));
- hormonal disorders (Congenital Hypothyroidism (CHT), Congenital Adrenal Hyperplasia (CAH)).

The prevalence at birth of the 11 detected congenital disorders.[12]

11 congenital disorders	**Total number of screened infants between 1 January 2012 and 31 December 2014**	**Total number of positive cases between 1 January 2012 and 31 December 2014**	**Prevalence at birth in Flanders**
Phenylketonuria (PKU)	202.713	24	1:8.446
Congenital Hypothyroidism (CHT)	202.713	58	1:3.495
Congenital adrenal hyperplasia (CAH)	202.713	14	1:14.480
Medium-chain acyl-CoA dehydrogenase deficiency (MCADD)	202.713	14	1:14.480
Multiple acyl-CoA dehydrogenase deficiency (MADD)	202.713	0	<1:202.713
Isovaleraemia (IVA)	202.713	3	1:67.571
Methyl malonacidemia (MMA) / Propionic Disease (PA)	202.713	10	1:20.271
Glutaric acid epidemic type 1 (GA1)	202.713	1	1:202.713
Maple Syrup Urine Disease (MSUD)	202.713	2	1:101.356

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[12] Vlaams bevolkingsonderzoek naar aangeboren aandoeningen bij pasgeborenen via een bloedstaal, Draaiboek, 21.06.2016, https://aangeboren.bevolkingsonderzoek.be/sites/default/files/atoms/files/draaiboek%2020161219.pdf

11 congenital disorders	Total number of screened infants between 1 January 2012 and 31 December 2014	Total number of positive cases between 1 January 2012 and 31 December 2014	Prevalence at birth in Flanders
Biotinidase deficiency	202.713	3	1:67.571

2.1.2 Bulgaria

According to the Bulgarian National statistical institute a total of 329 052 live births were recorded in Bulgaria for the period between 2013 and 2017; while the number for 2017 is 63 955 live births. Total fertility rate (TFR) is 1.54 children in 2016. [13].

According to the Bulgarian Association of Neonatology 9 % of all babies in 2010 were born prematurely (or born alive before 37 weeks of pregnancy are completed). The cities of Plovdiv, Sliven, Varna and Vratsa have the highest premature birth rates – about 20% for 2009.[14]

About 3% of all newborn children have congenital malformations or genetic defects. Thus, the frequency of these defects for Bulgaria (about 3%) is not different from the average for Europe. The majority of 60-70% of congenital malformations and genetic diseases are present in childbirth while 1 in every 40 newborn children has at least one significant anomaly which treatment would lead to a disturbance in normal development.

Some of the inborn defects occur in the child's later life, so the actual incidence of congenital abnormalities further reaches 4-6%. The most common abnormalities that occur at birth belong to the called multifactorial anomalies and generally account for 40-50% of all anomalies. The congenital heart malformations (frequency 4-6 per 1,000) are the most prevalent congenital abnormalities among live births, followed by central nervous system abnormalities (2-3 per 1,000). [15]

2.1.3 Romania

- **, In Romania, according to the bulletin no.11 / 2016 of the Ministry of Labor, in 2016 there were 190,238 children born, out of whom 103,645 in urban areas and 86,593 in rural areas.**

According to GD no. 655/2016 on the approval of the National Strategy "A barrier-free society for people with disabilities" 2016-2020 (published in the official gazette (Monitorul Oficial)) no.737 bis on September 22, 2016) on June 30, 2015, the rate of disabled people was 3.8% of the total population.

According to the National Authority for Protection of Children's Rights and Adoption (http://www.copii.ro/statistici/), on 31.03.2016 there were 71,798 children with disabilities in the evidence of the Complex Assessment Services of the County DGASPC and in the evidence of Bucharest's sectors, out of which:

- 36,240 with severe handicap,
- 15,001 with a high degree of handicap

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[13] Bulgarian National statistical institute
[14] Foundation "Our Premature Children"
[15] The prevalence of newborns with congenital anomalies in Bulgaria

- 18,910 with medium degree of handicap and
- 1647 slightly disabled

Regarding the age, there are:

- **9,813 children up to 2 years, out of whom 451 slightly disabled, 4382 with a medium disability level, 1418 with accentuated handicap and 3562 with severe handicap**
- 15.324 aged between 3 and 6 years old
- 30.114 aged between 7 and 13 years old
- 16.547 between 14 and 17 years old.

- **We have NOT found public ward-level statistics that can be used for future research or for informing the parents before choosing a hospital. Moreover, we have not found public statistics on the prevalence of congenital anomalies among newborns.**

- We have turned to EUROCAT (European surveillance of congenital anomalies) http://www.eurocat-network.eu/accessprevalencedata/prevalencetables , in order to understand the rate of congenital anomalies in our country. EUROCAT is the main source of information on the epidemiology of congenital anomalies in Europe. By comparing records from different years, it can be seen that the rate of congenital anomalies stalls at a similar level.

	2006-2010		2008-2012		2011-2015	
Congenital	LB+FD+TOPFA	LB	LB+FD +TOPFA		LB+FD+TOPFA	LB
All	25.5 per 1000 birth	**20.9** per 1000 births	26.1		**25.7**	**20.7 per 1000**
Down		**0.97** per 1000				**0.96per 1000**

LB = Live Births
FD = Fetal Deaths/stillbirths from 20 weeks of gestation
TOPFA = Termination of pregnancy for a fetal anomaly following prenatal diagnosis

- According to another European Perinatal Health Report (EPHR), 2006-2010, congenital abnormalities can be caused by genetic or environmental factors, or the interaction of both, but the exact cause of these anomalies remains mostly unknown.
- Major congenital anomalies are defined within EUROCAT and are associated both with a high mortality rate and other severe medical and functional consequences. However, in spite of the mortality caused by congenital abnormalities and as can be seen from the EUROCAT report, the vast majority of cases in Europe are the ones of children born alive, who survive childhood but who may have special medical, social and educational needs.
  - The largest subgroup of congenital abnormalities are congenital heart defects, with a live birth rate of 7.3 to 1,000 births
  - Limb defects at a rate of 3.7 per 1000 births
  - Urinary system defects at a rate of 2.85 per 1000 births
  - Chromosomal abnormalities have a rate of 1.48 per 1000 births, of which Down syndrome has a rate of 0.97 per 1000 births
  - Abnormalities of the digestive system have a rate of 1.53 per 1000 births
  - Orofacial clefts have a rate of 1.32 per 1000 births
  - Defects of the nervous system have a rate of 1.23 per 1000 births

- According to EPHR, 1 child in 500 suffers of cerebral palsy

Prematurity

- In Romania, premature is the birth before the 37th gestation week, and when the baby weighs 2500 g
- Premature birth is a major problem for infant mortality and morbidity (neuro-sensory and cognitive disabilities)
- The number of premature births in 2016 was of 18,000, which means a 9.45% prematurity rate
- 20% of premature births occur faster than 32 gestational weeks, requiring intensive care over a long period of time (approximately 3,600 children in 2016)
- According to the study "Trend of Premature Births in Europe", which studied the prevalence of live births in 19 European countries in 1996, 2000, 20004 and 2008, babies born under 32 gestational weeks faced an increased risk of adverse effects at a rate of infantile mortality of 10-15% and cerebral palsy of 5-10%.
- The infant mortality rate in 2016 was of 7.4 children deceased under 1 year of age per 1,000 live births. There is no known mortality rate among premature babies.
- The main causes of premature birth are: mother's old age, fertility pregnancies, twin pregnancies, previous medical problems, medical problems during pregnancy, low socio-economic status, lifestyle factors - exhaustive smoking, alcohol consumption, drugs, high stress.

2.1.4 Turkey

The population of Turkey is 81 million 890 thousand. The population of children (0-14 age) is 19 million 326 thousand[16] The total number of still birth is 1.309.771 at 2016 in Turkey[17]. The prevalence of premature birth is 12% in Turkey[18] 157,000 babies are born early each year when the birth population and preterm birth rate are calculated. The prevalence of cerebral palsy is 4.4 per 1000 live births[19]. We can say approximately 5,250 babies are diagnosed with cerebral palsy every year. There is no national registration of cerebral palsy in Turkey. The total number of disabled children attending primary, secondary and high school education is 306 thousand[20]. The prevalence of developmental delay was 6.4% aged 3-60 months[21]. Turkey has seven different regions according to geographically, socially, cultural characteristics. So that the rates of premature birth and congenital anomalies are changeable from region to region. There are different congenital anomalies rates in different regions. There is one study from Denizli, which is in Aegean region; the rate of congenital anomalies is 2.9 per 1000 live births. The other study from Van, which is in East Anatolia, the rate of congenital anomalies, is 2.9%. Lastly in Tokat which is in Black sea region the rate is 2%[22]. According to Tomatır's study, congenital anomalies' rate is %0.29, in 63.159 live births between 2000 and 2004[23]. During the 5-year study period in Istanbul, the congenital abnormities rate was %2.07[24].

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[16] TUİK, Nüfus Kayıt Sistemi Sonuçları. 2017; Available from: http://www.tuik.gov.tr/HbGetirHTML.do?id=27587.

[17] TUİK, Doğum İstatistikleri. 2016; Available from: http://www.tuik.gov.tr/PreHaberBultenleri.do?id=24647.

[18] Organization, W.H., Born too soon: the global action report on preterm birth. 2012.

[19] Serdaroğlu, A., et al., Prevalence of cerebral palsy in Turkish children between the ages of 2 and 16 years. Developmental medicine and child neurology, 2006. 48(6): p. 413-416.

[20] Yılmaz, İ. Sözlü Soru Önergesi Cevabı. 2017; Available from: http://www.egitimajansi.com/haber/engelli-ogrenci-sayisi-300-bini-asti-haberi-58992h.html.

[21] 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.

[22] Bülent Çakmak, Y.H., Tülay Aysal, Zeki Özsoy, Fazlı Demirtürk, Major Konjenital Anomaliler: Gaziosmanpaşa Üniversitesi Üç Yıllık Deneyim. Gaziosmanpaşa Üniversitesi Tıp Fakültesi Dergisi, 2012. 4.

[23] A.G. Tomatır, H. Demirhan, H.Ç.Sorgun, A.Köksal, F.Özerdem, V.Çilengir. Major Congenital anomalies: a five-year restrospective regional study in Turkey. Genetics and Molecular Research 8(1):19-27(2009)

[24] Oztarhan K, Gedikbasi A, Yildirim D, Arslan O. Adal E. Kavuncuoglu S. Ozbek S. Ceylan Y. Prevalance and distribution of congenital abnomalies in Turkey: differences between the prenatal and postnatal periods. Congenit Anom (Kyoto). 2010. Dec;50(4):221-5.

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2.1.5 Conclusion

Despite the lack of reliable data from all countries in Europe, these are the datas that public can access:
Disabled people represent 80 million persons in the European Union (more than 15% of the population), the equivalent to the population of Belgium, the Czech Republic, Greece, Hungary and the Netherlands together. (European Disability Forum).

One in four Europeans has a family member with a disability. Six Europeans out of ten know someone, in close or more distant circles, who has a disability. (European Disability Forum). People with reduced mobility represent more than 40% of the population. (European Disability Forum).

5.2 million births in the EU each year, approximately 104,000 (2%) will be born with congenital anomalies (WHO).

In 2008, preterm birth rates across Europe ranged from 5.5to 11.1% for all live births, from 4.3 to 8.7% for singleton births, and from 42.2 to 77.8% for multiple births. The annual percentage increases in preterm birth were significantly >0 in 13 out of the 19 countries included in the study for all live births.[25]

2.2 State of the art of the medical and other staff, timing, and their roles during the prenatal, natal and post-natal follow up

2.2.1 Flanders (Belgium)

There are Neonatal Intensive Care units in:

- AZ St. Jan (Bruges)
- GZA St Augustinus (Antwerp)
- Sint-Vincentius (Rocourt)
- UZ Antwerp
- UZ Brussels

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[25] Zeitlin J, Szamotulska K, Drewniak N, Mohangoo AD, Chalmers J, Sakkeus L, Irgens L, Gatt M, Gissler M, Blondel B; Euro-Peristat Preterm Study Group. Preterm birth time trends in Europe: a study of 19 countries. BJOG. 2013 Oct;120(11):1356-65. doi: 10.1111/1471-0528.12281. Epub 2013 May 24.

- UZ Ghent
- UZ Leuven
- Ziekenhuis Oost-Limburg (Genk)
- ZNA Middelheim (Antwerp)

Who are the first contact health/medical professionals during the prenatal, natal and post-natal periods

- Doctor-gynaecologist X
- Midwives X
- Genetic expert X
- Neonatologist X
- Paediatrician X
- Paediatric nurse X - pediatrisch verpleegkundige
- Psychologist X
- Nurse X
- Other

A neonatal ward is a specialized department of the hospital where sick, too small and premature babies are admitted. In this department the baby is continuously monitored under the supervision of a midwife or paediatric nurse. Here the baby gets the specific worries adapted this needs.

The team takes care of the development of the baby in accordance with the development-oriented care method.

The most common reasons for admission are:

- premature birth (less than 36 weeks of pregnancy)
- too low birth weight for gestational age (less than 2,300g) (dysmaturia)
- breathing problems
- infection incurred before, during or after birth
- severe birth defects
- observation after difficult delivery
- newborns of mothers with a disease (e.g. diabetes)
- serious nutritional problems
- temperature problems

The team consists of:

- Neonatologists: A paediatrician with a specific education and professional title for intensive care for newborns
- Medical head: A neonatologist who bears the final responsibility for the medical team, in his absence the deputy head of department or a head of the clinic undertakes this task.

- Doctor (since the neonatology unit is an intensive department)
- ASO - A doctor in training: They are usually called 'assistant' and change at regular intervals.
- Head nurse and unit manager
- Nursing staff
  - Paediatric nurses
  - Midwives [26]
- Social worker: The social worker is part of the patient guidance service. Parents can go to the social worker for care and emotional support, psychosocial support, information and advice about the legislation on social security and social services, social-administrative information about the birth and admission of the child, and financial help questions.
- Psychologist: The psychologist helps the parents to get to know their baby's body language and gives tips on contact. The psychologist can also offer support in this difficult period.
- Other employees
  - Lactation specialists: Lactation specialists are specialists in guiding breast feeding and can give advice to parents and caregivers who experience or expect problems during breast feeding.
  - Physiotherapists
  - Speech therapist
  - Psychologist
  - Philosophical assistance
  - Patient guidance: social workers, intercultural mediators
  - Logistic employees
  - Cleaning staff

Maternity care

In Flanders, maternity nurses work integrated within maternity centres which are part of the family care services.

Article 1 of the Decree of 11 February 2003 of the Flemish Government concerning the integration of maternity centres within services for family care provides maternity care defined as "the totality of care, including supportive assistance in hygienic-care, domestic and psychosocial terms, which must be provided for the mother, her child and possibly her family, who have recently given birth, during the period of an average of

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[26] The Flemish organization of midwives (VLOV) refers to the internationally accepted description of the WHconcerning the definition of the profession of midwife.“A midwife is a person who, having been regularly admitted to a midwifery educational programme, duly recognised in the country in which it is located, has successfully completed the prescribed course of studies in midwifery and has acquired the requisite qualifications to be registered and / or legally licEnsed to practise midwifery. The midwife is recognised as a responsible and accountable professional who works in partnership with women to give the necessary support, care and advice during pregnancy, labour and the posto partum period, to conduct births on the midwife’s own responsibility and to provide care for the newborn and the infant. This care includes preventative measures, the promotion of normal birth, the detection of complications in mother and child, the accessing of medical care or other appropriate assistance and the carrying out of emergency measures. The midwife has an important task in health couno selling and education, not only for the women, but alswithin the family and the community. This work should involve antenatal education and preparation for parenthood and may extend twomen’s health, sexual or reproductive health and childcare. A midwife may practise in any setting including the home, community, hospitals, and clinics of health units.” (WHO, 2005)

ten days, which follows the birth and that the mother needs to regain physical and psychic strength." Within the literature study the term 'non-medical postnatal care' is used to indicate the 'maternity care' described above.

In Article 1 of the Flemish Government Decree of 17 January 2003 on the integration of maternity centres into family care services, a maternity centre is defined as 'a service providing maternity care'.

Home care has four pillars in Flanders, namely a Christian column (with, among others, Family help, Family care and Rural home care), a Liberal pillar (with Solidarity for the Family), a Socialist pillar (with Bond Moyson) and an Independent pillar (with Independent Homecare Associations and Partena).

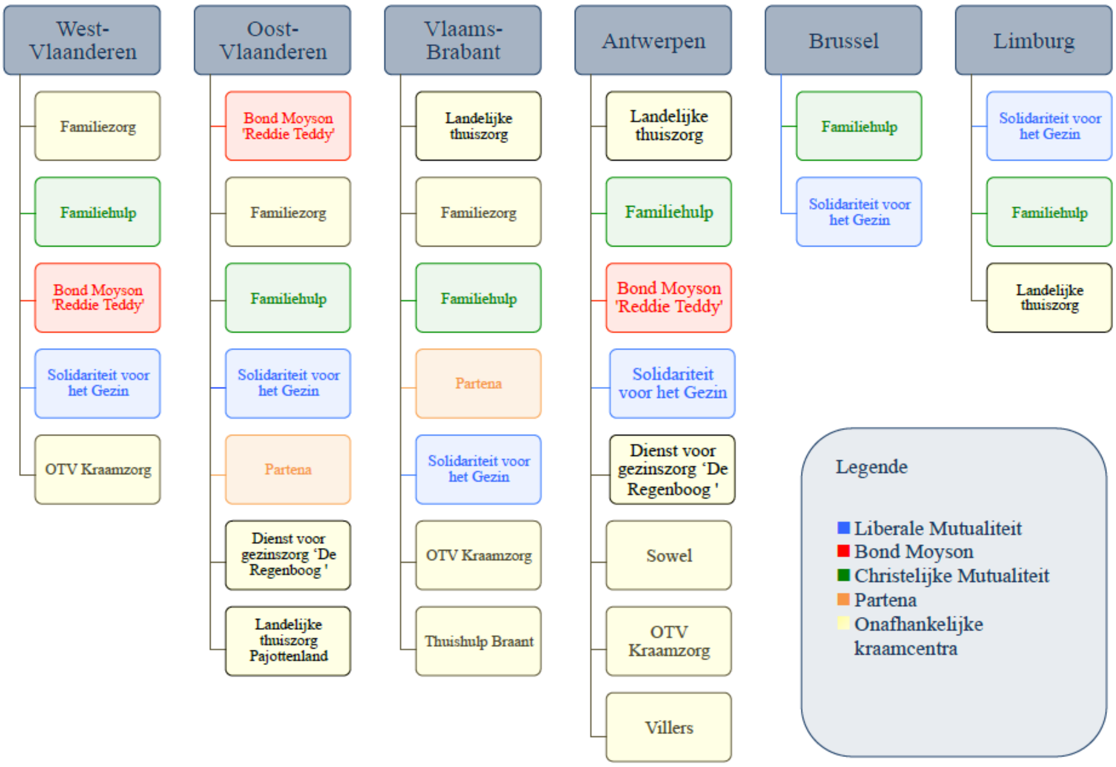

Figure 1: Major recognized providers of maternity care in Flanders 2014

Please describe in detail the currently existing referral process of newborn babies with complex needs (how and where?)

If at birth it appears that the baby has a disability (e.g. down syndrome), the Paediatrician will inform the parents. However, a disability is not always visible at birth. It is possible that a handicap is only established after a certain period of time.

Children born prematurely receive a special service after birth:

- NIZ (Neonatal Intensive Care) or NICU (Neonatal Intensive Care Unit): neonatal intensive care, for children born before a gestational age of 32 weeks

- N*: neonatal care linked to the maternity ward, for children born after a gestational period of 32 weeks, without the need for intensive care.

Babies born before a gestational age of 36 weeks are systematically admitted to a neonatal ward. In the department (intensive) care is administered.

Thanks to medical progress, the survival rate of preterm children has improved significantly. The dilute development of every child born early, however, is very individual. In general, the fewer complications during the stay in the neonatal ward, the better the future expectation.

With the ultrasound scans of the brain that occur in the neonatal departments one can predict or exclude important neurological problems. If this ultrasound indicates problems, they will be discussed with the parents in the neonatal department so that early treatment can be started.

Developmental Disorders Centres (COS)
In Flanders, all children born for a gestational period of 30 weeks and / or with a birth weight of less than 1250 grams are followed up. In the future this will be extended tall children born for a gestational age of 32 weeks or a birth weight of <1500 grams. This follow-up is done in the Centres for developmental disorders (COS). The COS are ambulatory diagnostic centres for children with or a suspicion of development delay or disorder. They detect developmental problems in babies and children and provide advice to parents and emergency responders.

The centres also report on the application for individual material assistance, the application of a personal budget or as an applicant for the Access Point for Integral Youth Support.

There are four COS in Flanders, recognized by the Flemish Agency for Persons with Disabilities (VAPH): in Antwerp (for adults only), Leuven, Ghent and Brussels:

- Oriëntatiecentrum
  Doorno straat 331
  2610 Wilrijk
  T 03 821 03 00
  F 03 828 69 64
- COS Brussel
  Laarbeeklaan 101
  1090 Brussel
  T 02 477 56 95
- COS Gent
  Campus UZ-Gent
  De Pintelaan 185 2K5
  9000 Gent
  T 09 332 57 44
- COS Leuven
  Kapucijnenvoer 33
  3000 Leuven

T 016 33 75 08

Operation of COS:

- Detection: COS tries to detect children with developmental disorders as early as possible.
- Diagnosis: A multidisciplinary team of doctors, psychologists, speech therapists, physiotherapists, an occupational therapist and social workers will map the possibilities and limitations of the child and, if necessary, make a diagnosis.
- Advice and orienteering: Based on the research results, the COS provides advice and orientates the child and the parents towards the most suitable aid offer.
- Scientific assignment: COS participates in scientific studies in children with developmental problems.

The COS not only looks at the limitations of the child, but especially at the (growth) possibilities. COS offers a broad range of care when giving advice. This can be both regular (reception, school) and specialized (a provision of the VAPH, a service within the Mental Health, private services, ...).

The COS itself offers no guidance or treatment. They only make a diagnosis if necessary and guarantee independent advice. They base their advice on the objective results of the research. The client decides whether or not to follow the advice.

COS focuses on:

- Infants and toddlers up t3 years old
- Preschoolers and primary school children up t7 years

Where there is a concern about:

- the general development
- the intellectual development
- communication, speech and language development
- the motor development
- behaviour
- social-emotional development

Step 1: Telephone contact

A parent can contact the social service of the relevant COS by telephone. In the telephone conversation it is checked whether the parent can turn to the COS. This is followed by a multidisciplinary diagnostic examination. Based on the research results, the COS provides advice on the further guidance and / or treatment of the child.

Step 2: intake interview

The research trajectory in the COS starts after the waiting time[27] with an intake interview with the parents. During this first conversation they listen to the concerns and questions about the development and behaviour of their child.

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[27] Voor kindjes tot 3 jaar is er geen wachttijd. Ze krijgen meestal onmiddellijk een afspraak. Aangezien de hoofdopdracht van het COS vroegdetectie is, is het belangrijk om, als er zich op een dergelijke jonge leeftijd problemen voordoen, hier zsnel mogelijk op in te spelen. Bij kinderen ouder dan 3 jaar wordt een

<u>Step 3: Possible examinations</u>
This conversation forms the basis of the various examinations at the COS:

- The doctor performs a clinical neurological examination with the child and the question about the development and behaviour of the parents.
- The psychologist investigates the general intelligence and possibly the behaviour (e.g. classroom observation, game observation, attention and concentration research).
- The physiotherapist examines the motor skills (gross and fine motor skills).
- The speech therapist evaluates communication, speech and language development.

<u>Step 4: Diagnosis and advice</u>
The multidisciplinary team (MDT) brings together the results of the various studies and, if necessary, makes a diagnosis.

The doctor and psychologist discuss the conclusions with the parents and give advice on the further approach and guidance. The parents will receive a written report.

<u>Step 5: Further (administrative) follow-up</u>
The COS can assist the parents in the further (administrative) follow-up of the research questions. They can assist them in requests for increased child benefit, certificates and / or prescriptions for treatment. Via the MDT operation they can submit an application file together with the parents for help, assistance or support from the Flemish Agency for Persons with Disabilities (VAPH).

The COS is recognized as MDT by submitting application documents (A documents) to the Youth Welfare Agency for possible support and adapted care from the Integrated Youth Assistance. Examples include school replacement day care for minors with disabilities, mobile and ambulatory assistance for minors with disabilities, ...

To receive support and care from the VAPH or youth welfare, the COS creates an A document together with the parents. This contains a clear description of the possibilities and limitations of the child and, if necessary, also diagnostic data are included.

COS is also a recognized team for the application of a Personal Assistance Budget (PAB) and for the application of Individual Material Assistance (aids).

The interview and the investigations take place in the COS and are spread over several days.

The follow-up of the child in the Centres for developmental disorders (COS) takes place at specific ages. We looked at different aspects of development: motor, mental and social development. In this way, children can be helped quickly if support is needed. The follow-up of the development takes place at specific ages:

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onderscheid gemaakt in de wachttijd afhankelijk van de vraagstelling. De wachttijd varieert tussen 6 en 15 maanden.

- At the corrected age of 4 months
- At the corrected age of 9 - 12 months
- At the calendar age of 2 years 3 months - 2 years 6 months
- At the calendar age of 4 years 6 months - 5 years 6 months

The corrected age is the age of the child minus the number of weeks that the child was born prematurely. Correcting for weeks of prematurity is very important, certainly until the age of 2 years.

At the corrected age of 4 months, the development of motor skills (movements) is examined. At that age important problems in the development of the movements can be excluded. If at that moment there is a problem with the tension in the muscles or the coordination of movements, then specialized physiotherapy can be started at an early stage. At this age it is of course also important that the baby follows and laughs smoothly. At 4 months, babies already have a beginning interest in toys.
At the corrected age of 4 months one will also discuss with the parents the behaviour of the child: is it irritable, is it crying often, is it going to overstretch, is it easy to comfort? Pre-born babies can be very irritable, which can be very tiring for the parents. Fortunately, it is often a passing phase. Tips from the home counselling services can work very well. It is also important that the parent knows that he / she can turn to the early treatment services for questions, even if the child is born after a 32-week gestation period.

At the corrected age of 9 -12 months, the development can be evaluated more extensively. The follow-up team again looks at the development of the movements. Now there can also be an evaluation of the mental (intellectual) development. By means of a fun test with toys, we examine which developmental age the child has. We also look again at social development and behavioural development. Parents and childcare are questioned via questionnaires. Any concerns or questions will be discussed with the psychologist and doctor. If necessary, one is also referred to a specialized physiotherapist or home counselling service.

At the calendar age of 2 years 3 months - 2 years 6 months the physiotherapist pays attention to the development of coarse motor coordination
and fine motor skills. The psychologist looks at the mental development. At this age, speech and language development will also be evaluated. This development is progressing well for most children. Some children have a little more difficulty in one or more development domains. Then it is examined whether some support is needed, e.g. in toddler groups in a rehabilitation centre. Children are always given enough time to catch up with the prematurity, but it is sometimes necessary to provide extra support for a child in kindergarten.

Between the calendar age of 4 years 6 months - 5 years 6 months the children are examined one last time by the COS team. At this age the evaluation is already more extensive, with a view to the learning skills for the primary school. In the evaluation of motor skills, attention is currently being paid to complex motor coordination, such as cycling and swimming. The fine motor skills, with specific writing motor skills, are evaluated. Often premature children have good intelligence, but there are some

problems with starting writing. This can give rise to frustrations. Some sessions with a psychomotor therapist can be of great help here. An intelligence test (development test) is also administered at this age. Two domains are being examined: the linguistic intelligence and the visual-spatial skills (important for preparatory calculations). Also in this domain a child can often keep up with extra support. In speech and language development, people look at the technical language and the understanding of small linguistic nuances at that age. Finally, the behaviour and social skills are discussed again. More extensive observations can be planned if the parent is concerned about social or communicative development. Especially children born for 28 weeks are more likely, e.g. problems with attention and concentration.
By following the children at these specific ages, the parents can always anticipate possible problems at an early stage. This early support often helps to avoid unrest and frustration. Many children born prematurely have a nice development in the future, but need extra support, especially in the first few years.

Kind en Gezin
Kind en Gezin (www.kindengezin.be) is an agency of the Flemish government. Its mission is to actively contribute to the well-being of young children and their families through services in the policy fields of preventive family support, childcare and adoption. Child and Family is there for all children, so also for children who need extra support.

Child and Family monitors the development of the child. For example, growth is closely monitored, taking into account the length of pregnancy achieved.
Also in preterm infants, vaccinations are started at 8 weeks. After all, babies born prematurely received fewer antibodies from their mothers, since the transport of antibodies mainly increases after the 35th week of pregnancy. With medical contraindications, the vaccination schedule can be deviated from. Children born after a gestational age of less than 37 weeks or with a birth weight lower than 2.5 kg are at increased risk of infection. They therefore receive an extra dose of the pneumococcal vaccine (at 12 weeks) and the vaccines that are normally provided at 15 months, they are brought forward at 13 months.

Contact groups:

- Prenatal
    - Emmanuël, Zwanger van een zorgenkind - http://www.emmanuel-zvzk.be
    - Met lege handen, Ouders van een overleden baby - http://www.metlegehanden.be
    - O.V.O.K, Ouders van een overleden kind - http://www.ovok.be
    - Fara vzw, informatie, begeleiding en verwerking bij prenatale diagnose - http://www.fara.be
- Postnatal
    - Gezin en Handicap, aanspreekpunt voor al wie te maken krijgt met handicap - http://www.gezinenhandicap.be
    - 'Eerste momenten', voor ouders met kinderen met een handicap - http://www.eerstemomenten.be
    - Trefpunt zelfhulp, ondersteuning en informatie voor en over zelfhulpgroepen - http://www.zelfhulp.be

Please describe in detail the currently existing referral process of newborn babies with complex needs (how and where?)

2.2.2 Bulgaria

According to the Bulgarian statistical institute **6174 medical professionals** were employed in the Departments of Obstetrics and gynaecology within the Bulgarian hospitals in 2016. The number of **obstetrics-gynaecologists** in Bulgaria is **1453**. They are responsible for the following procedures and medical services: pregnancy tracking, fetal morphology, prenatal biochemical screening, referral to other specialists and additional tests for genetic diseases, birth control, post-natal follow-up.

The number of **paediatricians** in Bulgaria is **1467**. They provide the following medical services: resuscitation of the newborn, detection of visible anomalies from the first examinations, conducting of additional laboratory, imaging studies and consultations, informing the parents about the condition and diagnosis of the child, training for the necessary care and additional consultations with different specialists; informing the relevant authorities of an anomaly detected.

The number of **midwifes** in Bulgaria is **3254**. They are responsible for the newborn care - toilet, feeding, and inoculation, venous manipulation, blood draw procedures and collection of human biological material for medical tests, training for parents on how to feed, dress up and bath their newborn.

There isn't official statistical data about the number of the **neonatologists** in Bulgaria, but according the professional opinion of prof. Boryana Slancheva[28] their number is **100-120 professionals**. Main responsibilities of the neonatologist are: monitoring and care for healthy newborns, adequate cardio-pulmonary adaptation of newborn children, timely and optimal in quality cardio-pulmonary resuscitation of risky newborn children, long-term treatment and observation of preterm infants with low and extremely low weight at birth, early and highly qualified diagnosis of all major nosological categories, providing high-tech complex intensive care, adequate specific therapeutic behaviour, monitoring the effect of the applied treatment, effective prevention and assessment of the late effects, etc.

Who are the first contact health/medical professionals during the prenatal, natal and post-natal periods?

The procedure in Bulgaria after pregnancy detection requires each pregnant woman to be directed to obstetrics – gynaecologists by her personal doctor (general practitioner). Obstetrics-gynaecologist is the medical professional who manages the pregnancy, labour, and puerperium and requires specific medical tests during the pregnancy period.

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[28] Prof. Boryana Slancheva is a Bulgarian professor in neonatology – national consultant in neonatology and head of the Neonatology Clinic under the largest University Obstetrics and Gynecology Hospital "Maichin Dom" - Sofia

This is the medical specialist who first informs parents if the medical examinations or tests detect abnormality in prenatal development of the foetus. He provides information about the diagnosis and the risks their child to acquire disability after birth.

Paediatricians and neonatologists are the medical professionals who first inform and communicate the medical status of the newborn soon after the birth. Neonatologist is involved both when a problem is identified during the prenatal phase and if the newborn is premature, and has a serious illness or injury.

Please describe in detail the currently existing referral process of newborn babies with complex needs (how and where?)

There is no existing formal/legal procedure for referring newborn babies with complex needs to complex medico-social providers. Each hospital establishes its own internal rules and procedures for referral process and develop own multidisciplinary professional network in order to provide medical, psychological and social support to the babies with complex needs and their families. The usual practice is hospital team on maternity ward level or psychologist and social work, if there are such specialists in the hospital, to contact the Regional directorate of Child protection department under Ministry of labour and social policy or to contact directly team for Early Intervention if such operates on the municipality level.

Since 2015 the neonatologists elaborate individual medical-social plans for each newborn with complex needs which include the regimen for tracing the child’s development. The plan indicates the medical specialists to who the child should be directed by the family doctor. The IMS plan is created in 3 copies – one is given to the mother, one is provided to the general practitioner (the family doctor) and one copy is kept in the neonatology department.

2.2.3 Romania

The Obstetrician-Gynecologist

The one who prepares the mother for the birth (examinations, necessary tests), checks her periodically, establishing whether a pregnancy is at risk and what this risk is (initiating the necessary treatment and if labor is triggered, he is responsible for the medication that decreases the mortality of the fetus and matures the lungs, he is responsible for sending the pregnant to a third-level center in case of prematurity). He takes part at birth and the subsequent check-ups of the mother, and is the one who requires screening and tests, fetal morphologies, recommends seeing other specialists for further tests in order to detect some genetic defects. The obstetrician / gynecologist is therefore the first person to inform and discuss with parents when examinations or medical tests detect certain abnormalities in the development of the fetus or when there is a risk of increased prematurity.

- In Romania, the pregnancy is followed-up by the obstetrician-gynecologist or the general practitioner, but one in 5 pregnancies is not followed at all.

- In the social health insurance system, pregnant women are insured, just like any other Romanian citizen but pregnant women who have no income or who earn less than the basic national gross minimum wage will benefit of unpaid health insurance.

- In addition to the basic health care package provided to any insured person, pregnant women are entitled to: **a series of laboratory tests, para clinical investigations and complex investigations**: Obstetrical ultrasound for abnormalities in 2nd trimester and Obstetrical ultrasound for abnormalities in first trimester with TN.

- Although the investigations are free of charge (according to the public health insurance system, even for pregnant women who do not receive income, according to CNAS Order no. 617/2007) (for 4D ultrasounds, to amniocentesis) if, for example, you are pregnant and you have to do a second morphological ultrasound of the fetus and the hospital's / clinic's budget has been exceeded, you will have to pay for it.

- Births can only occur in a public or private hospital - even if the pregnancy hadn't been followed up, the obstetrician-gynecologist is responsible for bringing the child into the world.

- Unfortunately, there is no collaboration protocol between the obstetrician and the neonatologist, not even when it is known that the mother will give birth prematurely or she is admitted to the hospital before birth with health problems, the dialogue being initiated, in most cases, only after the child is born.

After the child is born – suffering of various medical conditions or prematurity (if it is not known from the beginning what the problems are and the diagnosis cannot be determined for a certain period of time) – the child will stay in the hospital, in intensive or premature care, depending on the severity of the problems, until they are solved. If the child suffers of some health conditions or the maternity does not have an intensive care unit, it is possible to transfer the child to Bucharest or another county -either to a 3rd degree maternity hospital or to the Marie Curie Hospital (multidisciplinary hospital with multiple diagnostic and treatment facilities, to which many patients across the country are redirected, with varying and difficult pathologies, here being treated 30,000 children per year). Here, there is an intensive care unit dedicated to preemies with serious health conditions that annually treats about 200 newborns and even premature babies under 1000g with severe pathologies, digestive malformations, pulmonary malformations, diaphragmatic hernia, obstetrical trauma, severe infectious diseases, and neurosurgical conditions.

- In a 3rd Degree Maternity there are 3 departments:

- Department of Neonatology
- Department of Neonatology-Prematurity
- Neonatal Intensive Care Unit

In the neonatology departments are working:

- Neonatal Physicians - neonatology implies the intensive care of the newborns. It is a subspecialty that has pediatrics at the base, and the neonatologist has in-depth pediatric knowledge.
- Nurses.

Neonatologist

He is the one who, together with the obstetrician, is present at birth and intervenes in complex, high-risk situations or when the child comes into the world prematurely. He sets the diagnosis and treats the newborn's respiratory problems, infections or malformations, ensuring the coordination of medical care and adjustment to the new environment. He is the one to recommend, according to the condition, blood tests, imaging methods or specific screening tests in order to diagnose any disease. He collaborates with other specialists (neurologist, cardiologist) in order to establish the correct diagnosis for the child, to inform the parents and to guide them further.

- Genetic syndromes such as Down syndrome can be recognized by the neonatologist, who will guide parents on what they have to do.
- Normally, they work in maternity hospitals, taking care of hospitalized babies, so in most of the cases they do not take part in the follow-up after the baby is discharged.
- Is the first to make contact with parents and with the newborn with medical, congenital, premature conditions, and has the task of communicating this to parents and to guide them; unfortunately, communication with parents is done in the corridor, in the open, there are no spaces dedicated to the communication of such delicate news.

In Romania, a pregnancy is considered viable after the 24th gestational week, therefore resuscitation of babies under this age is only made at the express request of the parents.

Neonatology Nurse: assists the newborn’s care from the moment of birth to the discharging from the hospital, being skilled in newborn care, giving treatments decided by the neonatologist, taking care of vaccination for immunization (according to the national scheme). They also have the responsibility to communicate with mothers and to train them regarding breastfeeding, but they are not allowed to transmit medical information

- In fact, for premature mothers, the dialogue with nurses is very important, because they are the people the mothers see daily and the ones who often encourage and support them as well. They mostly mediate the communication with the neonatologist.

- There is an extremely low number of nurses in maternities, one taking care of 4-5 children in intensive care and there is only one nurse for every 10 preterm babies.

Neurologist - the one to whom the child will be referred by the pediatrician, neonatologist, general practitioner if there are suspicions, or to the emergency hospital (situation of epileptic children). He performs neurological and child development examination and can refer the child to a specialized psychiatrist, for genetic testing or to a physician / physiotherapist, if that is the case. For situations where the child suffers of a neurological problem that could not be detected previously (e.g. epilepsy, intraventricular bleeding when the neonatologist could not put the diagnosis at birth, the child needs to be followed up over time) he is the one who will communicate the diagnosis to the parents.

The physiotherapist - his presence in maternity hospitals would bring major benefits both in treating some momentary aspects - such as sucking and swallowing, improving respiratory function - but also in reporting any clinical aspect within his expertise, thus starting the process of early recovery and informing parents regarding the child's needs after leaving the hospital. Unfortunately, there are no physiotherapists in maternity medical teams in Romania, and in universities, there are no neonatology or neonatal recovery classes.

Although at ward level there should be a **social assistant**, in all hospitals having UGON units (a unit of gynecology, obstetrics and neonatology), according to a report by Salvați Copiii on the analysis of medical services, staff and equipment for newborns and obstetrics, there only are social assistants in 73 units. The Social Assistance Office should provide counselling when there is a risk of abandonment of the newborn, they should help in solving social problems, and collaborate with specialists in helping addicted mothers and ones suffering of postpartum depression.

The psychologist – the existence of a psychologist is not legally enforced in the maternity grid. He may be employed in the hospital but, in these situations, he is in charge of several departments and also conducts the evaluation activity, not just counseling. That is why there are extremely few cases where the mother gets to talk with the clinician psychologist during pregnancy, and this only at the specific request of the obstetrician.

- For situations where a medical diagnosis is discovered and a certificate of disability is required, the assessment by a clinical psychologist is required.

The **general practitioner** is the one who initially refers the pregnant to the obstetrician and the one to whom the family returns after discharge, for the baby's follow-ups. He is responsible for following the vaccination scheme and making recommendations for consultation with other specialists. In Romania, family doctors are general practitioners, very few of them are pediatricians, and parents can opt for child care with a pediatrician, paid of charge only with a referral ticket from the family doctor.

Please describe in detail the currently existing referral process of new-born babies with complex needs (how and where?)

The newborn remains in the hospital immediately after birth, as long as it is necessary for him to recover and for the doctors to carry out the complex investigations, the child being in the care of the neonatologist, who must inform the parents regarding the various problems. When life is no longer in danger, the child will be discharged, even if the exact diagnosis is not yet known, and in the case of prematurity, cerebral palsy or congenital abnormalities that are difficult to detect from the first moment, the diagnosis will be delayed with several months.

From the moment of the child's discharge, according to the legal procedures, he is taken into observation by a **family doctor(general practitioner)**, leaving it to the parents to decide whether the child will be followed-up by a pediatrician or neonatologist in the first year of his life. For specific problems and conditions, however, the family doctor will recommend to the parents specialist consultations, consultations that are free of charge based on the referral slip, according to the health insurance system. However, in most cases, the neonatologist will not participate in the follow-up of the newborn, once he leaves the maternity.

If the child does not have a diagnosis when leaving the hospital, but there are issues emerging in time, the investigations will continue until a medical diagnosis is received from the specialist physician, a diagnosis required for obtaining the disability certificate. This can be received by submitting several papers to the **Commission for Assessment and Certification of the Degree of Disability - within DGASPC of the district** / county of residence - among which the file that certifies the diagnosis of the child (primary, secondary and other associated diseases).

- The Complex Assessment of the Child with Disabilities within DGASPC identifies children with disabilities and learning and socio-school adjustment disabilities who require a disability certificate;
- In exceptional circumstances, performs the complex assessment of the child or its components at the child's home;
- Creates the complex evaluation report;
- Creates the recovery plan for the disabled child - access to specialized services of recovery, therapy;
- Draws up, according to the law the personalized protection plan for the child with disabilities;
- Suggests the Child Protection Commission within each sector / county to include the child in a category of disability (medium, severe, severe) and, if necessary, establishes a protection measure;
- Pursues the implementation of the child-recovery plan approved by the commission;
- Performs the annual re-evaluation of children who need to be classified as disabled (at their parents' or legal representative's request);

The applicant subsequently submits the Certificate of Classification of Disability (a copy) and the Medical Certificate A5 type (copy) together with the civil status papers for granting the rights related to the degree of disability.

In some counties, DGASPCs do not have sufficiently large recovery centers, staff or necessary equipment for treatment plans for all children, and some of them only target children over 3 years of age.

For example, DGASPC sector 2 provides recovery / rehabilitation services for the disabled child: occupational therapy, educational therapy; Ludo therapy; physiotherapy; speech therapy; counseling. Beneficiaries are children with multiple disabilities who possess a certificate of categorization in a disability category, aged 3 to 12, who come from families or who are placed in foster care of professional assistants, and are residing within sector 2.

In most cases, recovery programs are not available in the national system at the level of the child's actual needs and frequency, leaving it to each family to create a network of therapists to work with the child (speech therapy, kinesiotherapy, occupational therapy and others), and to pay for all these hours.

There are also service centers for children with disabilities where accommodation, nurturing, education, physical and psychological recovery, socialization for children with disabilities from disadvantaged social backgrounds, single parent and disorganized families are provided, but these are only offered for a definite period of time.

2.2.4 Turkey

- **Midwives:** Are not always first contact person in the prenatal and perinatal period. However, if the birth is performed at the midwifery control and the first contact with the baby is the midwife; If the midwife (the midwife with the NRP "neonatal resuscitation program" certificate) is needed for the disabled babies as well as the newborns, the resuscitation in the delivery room is followed by the stabilization of the newborns (body heat, respiration, circulation) and transportation to the neonatal intensive care unit is ensured under suitable conditions. If neonatal transport occurs between hospitals; In this process special position, care is provided for the baby's condition and the treatment is ordered. Providing stabilization of baby before transportation in all neonatal transports is the basic principle.

- **Gynecologists:** Gynecologists follow the mothers and infants in the prenatal period. If there is a problem which will be cause developmental problem of baby such as structural or genetics than perinatology department adding to follow up process.

- A pediatrician is available at the time of delivery. After the birth, the pediatricians follow the baby and control the baby's vital functions, make the vaccinations in the national program. If the baby needs an intensive care, pediatrician will perform the transfer. The neonatologist also contributes to this process. All infants in the neonatal intensive care unit are referred to the pediatric neurologist. However, in practice, if the pediatrician suspects a developmental risk, it will direct the child neurology. Sometimes it can take up to two years.

- **Neonatologist:** By applying the medical principles and methods within the knowledge, skills and attitudes gained during medical and specialist education, take preventive measures for the individual and the society from health problems, diseases and injuries; diagnose, treat and rehabilitate and work to prevent possible complications. The neonatologist tries to keep the baby alive and stabilize the situation. They make appropriate interventions in emergency conditions. The first contact persons of children with disabilities in our country are obstetricians and pediatricians, who examine newborn babies. If the newborn resides in the intensive care unit, the coordinator is the neonatologist. In other cases, the child's neurologist, genetic or other specialized doctors have the authority to co-operate with other specialists to manage problems with the child, according to the child's defect.

- **Child neurologist:** the child's neurologist diagnoses the problem with neurological examination, imaging and developmental assessment, he/she directs it to physical medicine and rehabilitation specialist and child psychiatrist. If the hospital has the authority to issue a disabled health board report, the report will be issued. If the authority is not available, it will be directed to the pediatrician who works in authority hospital. After that pediatrician refer the baby child neurologist and disabled health board report is given. The child neurologist is a key person to diagnose or referring other doctors such as genetic expert. The subsequent process continues as described in “section 2.3.4”.

Please describe in detail the currently existing referral process of newborn babies with complex needs (how and where?)

- **Psychologists:** Psychologists have received relevant certified training in psychology undergraduate studies and/or proficiency to provide psychological support services for disaster and crisis and private areas.

- **Nurses:** Nurses support the family in crisis periods that cause anxiety and stress in families such as birth with anomalies, premature birth, low birth weight or loss of baby. The nurse evaluates the newborn and informs the physician when there is a problem with the newborn. Neonatal nurse ensures the preservation and maintenance of the body heat of the newborn. Nurse helps the family to start interaction with baby at the earliest possible time; therefore nurse meets the mother's needs and evaluates the quality of the relationship between mother and baby. They take precautions to prevent newborn infections. The newborn nurse ensures that the patient is transported safely when needed and prepares all conditions for newborn transport. They are always in contact with the parents. The nurse evaluates the level of education of the mother at every step of the baby care. They guide the family at all levels of care for the protection and development of the baby's health.
  - Neonatal nurses also work in neonatal intensive care units. They are responsible for all the care of the babies in neonatal intensive care units. They provide babies care including the breastfeeding, kangaroo care, skin care, etc. training before and after discharge. The list of physicians and should be done to follow the development is given to the mother. After discharge from NICU family physician adding to process. Family physicians and nursing or midwives make height, weight, vaccination and general health checks to mother and baby[29].

2.2.5 Conclusion

In the prenatal, natal and postnatal period, gynecologists and midwives usually encounter the family. In the prenatal period, nurses communicate with parents for birth and breastfeeding trainings. If the baby is born with a detected and seen disability and is admitted to the neonatal intensive care unit, the family is confronted with neonatologist, newborn nurse, pediatrician and other specialist pediatricians according to their needs.

2.3 Legislation and policies for babies with disabilities and complex needs, and their parents

2.3.1 Flanders (Belgium)

Fragmented division of powers

Belgium is a federal state that consists of communities and regions.

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[29] http://www.resmigazete.gov.tr/eskiler/2014/05/20140522.pdf page 17

The current disability policy is divided among several authorization levels:

- the federal government,
- the communities,
- the regions,
- the municipalities.

For the family of a child with a disability it is particularly complex to know from which government one can obtain which benefits and assistance.

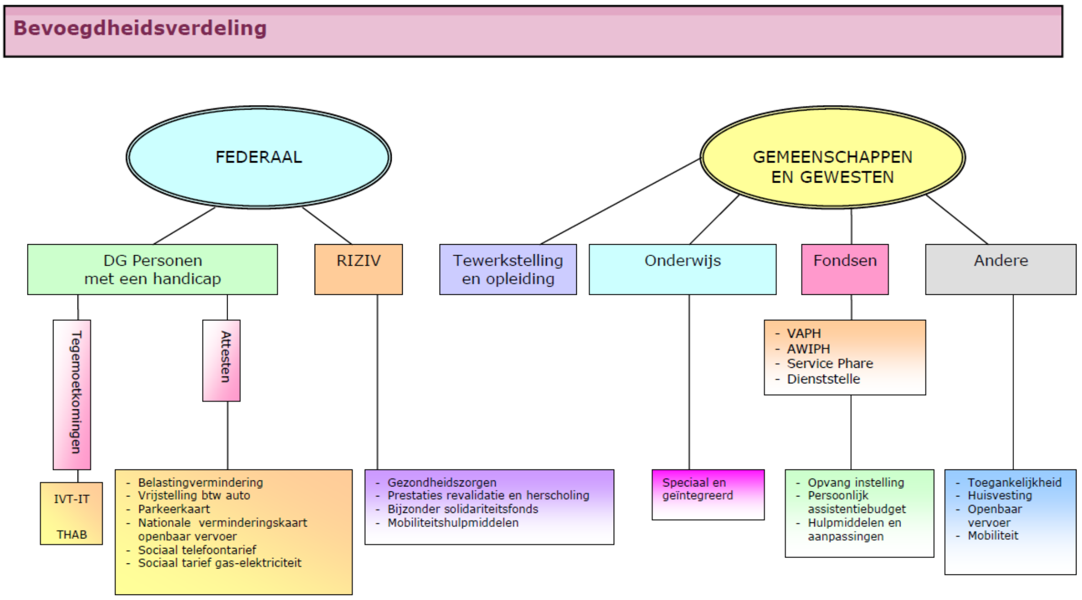

Figure 2: Bevoegdheidsverdeling

Vlaams Agentschap voor Personen met een Handicap (VAPH)

The Flemish Agency for Persons with Disabilities (VAPH) is an agency of the Flemish government and is part of the policy domain Welfare, Public Health and Family. The VAPH aims to promote the participation, integration and equality of opportunities for Persons with disabilities in all areas of social life. The VAPH subsidizes people with disabilities and services or facilities for these Persons. Work is being done on future perspectives and on responding to changes in the needs and age structures of the target group. In short, a policy that is fully geared to the optimal integration of people with disabilities in our society.

Decree of 7 May 2004 establishing the internal privatized agency with legal personality Flemish Agency for Persons with Disabilities (B.S.11.VI.2004),
Changed at:
B.Vl.Reg.inw.1.IV.2006 with the exception of:
a) Article 32, 1 ° and 2 °;
b) Article 32, 3 °, insofar as it concerns the provisions, stated in Article 62, as at 1.I.2007.

Kind & Gezin

Child and Family (K & G) was initially established as a Flemish public institution by decree of 29 May 1984, and this as a successor to the National Work for Child Welfare (NWK). The effective operation started on 1 February 1987.

The Decree of 30 April 2004 re-established Kind en Gezin (in the context of BBB) as an internal independent agency with legal personality. This decree came into effect on 1 April 2006.[30]

Centra voor ontwikkelingsstoornissen (COS)
The recognition and subsidization of the centres for developmental disorders is laid down in the decision of the Flemish government of 16 June 1998 to regulate the recognition and subsidization of the centres for developmental disorders.[31]

UN Convention on the Rights of Persons with Disabilities
The UN Convention on the Rights of Persons with Disabilities was voted on 13 December 2006 at the United Nations Headquarters in New York and proposed for signature from 30 March 2007. Belgium signed on 30 March 2007 and ratified on 2 July 2009, with entry into force on 1 August 2009 at national level.

Law concerning termination of pregnancy
Due to the Act concerning the termination of pregnancy of 3 April 1990[32] , abortion is no longer punishable under certain conditions. The law amended articles 348, 350, 351 and 352 of the Criminal Code (Title VII - Crimes and offenses against the order of the family and against public morality, Chapter I - Abortion) and lifted Article 353.

In principle, abortion provocatus remains a crime, except in two cases provided by article 350 of the penal code.

- Termination before the end of the 12th week

The first case is when the procedure is performed during the first 12 weeks after fertilization and the following conditions are met:
    - the pregnant woman declares that she is in an emergency situation;
    - the intervention must be carried out by a doctor under medically justified circumstances in a health care institution that informs the pregnant woman of all laws and decrees that could help her to resolve her emergency situation;
    - the doctor carries out the operation at the earliest six days after the first consultation;
    - the doctor informs the woman about the medical risks to which she is exposed;
    - the doctor must remind the different childcare facilities for the child that will be born;
    - the doctor has to confirm himself of the woman's will.
- Termination after the 12th week

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[30] https://overheid.vlaanderen.be/kind-en-gezin-kg
[31] https://www.vlaanderen.be/nl/nbwa-news-message-document/document/090135578021318a
[32] Wet betreffende de zwangerschapsafbreking, Belgisch Staatsblad, 5 april 1990, http://reflex.raadvst-consetat.be/reflex/pdf/Mbbs/1990/04/05/10906.pdf

The second case provides for abortion of the unborn child after the 12th week to the full-term baby (average 40th week) if:

- the completion of the pregnancy poses a serious danger to the health of the woman or if it is certain that the child that will be born, will suffer from an extremely serious ailment that is recognized as incurable at the time of the diagnosis, and
- advice was requested from a second doctor.

A doctor, nurse or a member of the paramedical staff cannot be obliged to cooperate with abortion provocatus. A doctor who refuses to perform such an operation is obliged to inform the woman on her first visit but is not obliged to refer her to another doctor. The law does not define the terms "emergency situation", "extremely serious ailment" and "medically justified circumstances" and clearly states that the father of the child has no say in the decision whether or not to carry out an abortion. It is the woman who sovereignly fulfils the concept of emergency.

2.3.2 Bulgaria

Newborns and babies with complex needs are subject to the legislation in the fields of: child protection, integration of people with disabilities and medical care. The main legislation acts related to medical-social care and protection of babies with complex needs are:

- Child Protection Act
- Family Allowances Act
- Law on the integration of people with disabilities
- Health Act

With regards to the health care National law in Bulgaria gives priority to the children aged up to 1 year. The control over provision of medical and social care for children aged up to three years is exercised by the Bulgarian Minister of Health. Children accommodated at medical treatment facilities founded by the state shall be entitled to medical and social care free of charge. Mothers of infants are granted with free access to medical treatment facilities for specialised outpatient out aid health care.

Bulgarian Health act also requires medical professionals to notify the Social Assistance Directorate with jurisdiction over their respective medical establishment facility about each child born at that establishment facility who is at risk of being abandoned.

According to the child protection legislation children with disabilities should be treated by the authorities as children at risk. As such they have right to receive specialised assistance, support and services rendered in their family environment or to be placed in specialise medico-social institutions. Child protection in the field of medico-social care is implemented by the State Agency for Child Protection, Social assistance directorates, Regional health inspectorates and the mayors of municipalities.

Under Family allowance act the Social Assistance Agency performs activities related to the provision of family allowances for children (upon childbirth and for raising child).

National policy related to the premature babies and babies with congenital disabilities has been transformed during the last years.

Influenced by the European practices in the field and because of the social pressure, Bulgarian policy makers and the experts in medical and social care systems have changed the methodology of care provision to babies with complex needs. As a result, the medical care provision model shifted to holistic model of support. The medical standards for paediatrics, obstetrics-gynaecology and neonatology have been modified in order to observe the need of medico-social support and care of babies with complex needs and their families. Medical experts are engaged in multidisciplinary and multipartite collaboration with experts from various fields and social sectors. Apart from the medical treatment and medical care, they also communicate the new family situation with the parents of babies with complex needs, explaining them the medical diagnosis of their baby, and requiring treatment and care, as well as the medical and non-medical specialists that parents should contact.

2.3.3 Romania

The legal provisions are mostly published on the DGASPC websites, along with other information on the necessary documents in order receive the disability certificate, recovery centers for children and adults, services offered, etc.

• First of all, at the country level, we have the **National Strategy "A barrier-free society for people with disabilities" 2016-2020**, followed by the **operational plan** for its implementation. The strategy aims at ensuring the implementation of the **Convention on the Rights of Persons with Disabilities, ratified by Romania through Law 221/2010,** through a coherent, integrated and institutional set of measures.

The Convention provides a framework for public policy development and modernization of practices, tools and ways of community support that will lead to the full participation of people with disabilities in society, to a dignified and fulfilled community life.

General objectives - to promote accessibility, to ensure participation, to eliminate discrimination and to ensure equality, to ensure this in open, inclusive environments, to promote inclusive education and training, to substantiate policies and to ensure the fair access of people with disabilities to quality health services, at a reasonable cost and as close as possible to the communities in which they live.

One of the goals also refers to habilitation and rehabilitation, more exactly to those effective and appropriate, personalized measures, including the provision of assistive technologies and devices and mutual support between people with the same problems, enabling people with disabilities to obtain and maintain maximum of autonomy and to develop their physical, mental, social, educational and professional potential for full integration and participation in all aspects of life.

- **Law 448/2006 on the protection and promotion of the rights of persons with disabilities**

According to this law, you can obtain the disability certificate that gives the child and the family certain rights:

- A higher allowance (200 Law 61/1993 on state child allowance),
- Additional monthly personal budget, regardless of income, but depending on the degree of handicap (50/150/250 RON)

- Financial incentive, only for Bucharest, 1000 lei worth, sum that can be spent however the family decides, the sums spent not being justified with documents
- For children with severe disabilities, the family has the right to choose whether one of the parents will become the personal assistant of the child, with an individual employment contract concluded with the City Hall where the disabled person resides (paid from public funds according to Law 153/2017, having right to: 40 working hours per week, annual leave, free public transportation) or will choose to receive a child allowance in the amount of 1162 lei, from DGASPC.

Also, the preschool or disabled pupil and his companion also benefit from free camps in rest camps, free transportation, tax exemption on buildings and lands, exemption from paying interest on credits with the purchase of a car or the adjustment of a home and so on

- **Law 292/2011 - Social Assistance Law**

- **National Education Law 1/2011** - Children and young people with special educational needs can be integrated into mass education and to benefit from educational support from the support and itinerant teaching staff, on a case-by-case basis.

The organization of educational support services is within the scope of CJRAE / CMBRAE and is regulated by specific methodologies developed by the Ministry of Education, Research, Youth and Sport.
In fact, a large number of parents who opt for the child's integration in mass education have to pay by themselves for a person to accompany their child to school, they have to pay for the child support activity with the school psychologist / psycho-pedagogue, most of times only 1h / week.
Children and young people with special educational needs, enrolled in special or mass educational establishments, including those in a county other than their homeland, benefit from social assistance consisting of the provision of a daily food allowance, school supplies, pillows, blankets, sheets, clothes and shoes in an amount equal to the one for the children who are in the Child Protection System, as well as free accommodation in boarding schools or the assistance centers for children with special educational needs within the county / Bucharest general directorates for social assistance and child protection.

2.3.4 Turkey

The process begins with the baby being diagnosed with the disability health board report. The disability health 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. Special Education Evaluation Board in guidance research center makes assessment with objective, standardized tests and measurement tools appropriate to the characteristics of the individual. With this evaluation, an educational diagnosis is made. Assessments are including; 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.

Children in school age can be directed to inclusive education, special education class or special education school.

Inclusive Education

The education of the individuals who need special education is provided with supportive education services, and together with their typical development peers, preschool, primary school, junior high school, high school and special education institutions.

Special Education Class

Special education classes that are opened to all types of official and private schools / institutions for individuals who are in need of special education and are eligible to receive education in a separate class. The aim of this class is study together with nondisabled peers

Special Education School

The guidance research center may also refer to the special education school according to the evaluation result.[33]

2.3.5 Conclusion

Legislation and policies vary from country to country in EU.

2.4 Medical Care services available for (disabled) newborn babies (including services at home)

2.4.1 Flanders (Belgium)

As described earlier, the Centres for Developmental Disorders (COS) and Kind & Gezin provide this role and provide the necessary support.

2.4.2 Bulgaria

During the puerperium the newborn with complex needs receives physical therapy and medical treatment, professional rehabilitation and various medico-social services. Medical care services might be provided at specialised hospital departments or centres like Homes for medico-social care for children, Complexes for integrated health and social services for children from 0-7 years, Family type accommodation centres for children aged 0-3 with disabilities, Centres for Maternal and Child Healthcare for children with disabilities aged 0-3 years, Daily care centres for children with disabilities aged 0-3.

Early Intervention teams and “Mother and baby” Units under Complexes for social services for children and families also provide medico-social services. Early Intervention teams include paediatrician and other medical specialist if it is required,

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[33] Özel Eğitim ve Rehabilitasyon Hizmetleri Genel Müdürlüğü, T.C.M.E.B., Rehberlik ve Araştırma Merkezi Kılavuzu. 2018; Available from: https://orgm.meb.gov.tr/meb_iys_dosyalar/2018_01/17234231_ram_kilavuzu_2018.pdf

specially trained medical nurse or midwife, rehabilitation therapist, psychologist, social worker and speech therapist. The team provides medical and social care at home – medical treatment, rehabilitation, training of parents on baby feeding, bathing and dressing, feeding therapy, psychological support, consultation and application for social care services and state funding, etc.

Bulgarian Ministry of Health Care establish RULES about the structure, activity and internal order of the complex centres servicing children with disabilities and chronic diseases in 2017, but such centres have not been founded in Bulgaria so far.

2.4.3 Romania

- During hospitalization, medical services - investigations, medication and possible interventions - are free, according to the General Agreement on the Conditions for Medical Assistance under the Social Health Insurance System.

  However, due to insufficient funds or the impossibility to perform complex interventions – either they are not valid in our country or they can be done in only one place and there is a waiting list - if the newborn has medical problems or suffers of some disabilities, parents often have to turn to private hospitals in the country or abroad.

  For example, pediatric cardiology has 2 centers in the country- Marie Curie and Târgu Mureș, insufficient for the number of cases and many children are transferred abroad for interventions, which are settled by the government only if the interventions cannot be performed in the country.

- Neonatal screening (mandatory testing of all newborns) for: phenylketonuria, hypothyroidism and deafness

- Vaccinations are carried out according to the legislation in force in Romania (if parents agree): anti-hepatitis B and anti-tuberculosis (B.C.G.)

Prematurity

- There are 180 maternities in Romania, out of which 20 take care of babies born in 24-40 weeks (3rd Degree Maternity), 40 of them can take care of children starting with 32 weeks (2nd Degree) and the rest take care of term-born babies. Taking into account the prematurity rate, of almost 10 %, these are insufficient for the number of premature infants.
- If the child is born in a maternity hospital without the necessary room for his degree of prematurity and he needs to be transferred, there are only 5 mobile adapted neonatal units all over the country.
- Even though the baby has various congenital abnormalities or complex needs (case of premature babies), there is no maternity-based multidisciplinary team for early assessment and intervention – specialized doctors, physical therapists, psychologists, neurologists - to investigate and explain to parents the child's

affection and the necessary steps to be followed to ensure recovery and to ensure an early intervention plan.

- In Romania, regarding neonatal intensive care units, there is no unit equipped with individual child care units, there usually are 5-7 incubators in a room, in a restricted space.
- Also, in none of the intensive care units are implemented the family center principles that reduce light, decibel levels, correct baby positioning, and parental involvement in child care and pain management.

2.4.4 Turkey

In accordance with the topic "Evaluation of Early Childhood Rehabilitation Services in Turkey 'is the theme of a workshop organized in 2014 and communicated to the relevant authorities report the results. However there is still no progress on the subject. With the date of 01.02.2010 and numbered 3895 of the Ministry of Health, it has been started to give home health services in our country. With the approval of the authority dated 24.02.2011 and numbered 8751, the new directive came into force. The group that can benefit from our Home Health Care Scope is only newborns (0-1 month old) who need phototherapy.

Despite the variety of medical support in neonatal intensive care units, there are shortcomings in early intervention modalities such as positioning the baby and adjusting the light level for the baby.

There are special companies that provide newborn and premature care services at home and support healthy infants but the wage policy is quite high.

2.4.5 Conclusion

The results vary according to the number of experts and medical equipment of each country in EU. In every European country there are different baby care and early intervention teams. In countries where early intervention teams are not available, care of babies with complex needs is done by specialist doctors at the first meeting with disabled babies, referring to other specialist doctors according to the baby's needs.

2.5 Psychosocial support to parents with (disabled) newborn babies

2.5.1 Flanders (Belgium)

Shortly after the diagnosis, the emotional processing of the developmental delay or the limitation of parents plays a major role. Then it is important to 'be there', to follow the pace of the parents themselves, not to offer a heavy program. Psychosocial support is crucial in this. Research[34] among actors from the regular sector indicates that they do not have the necessary expertise to adequately support parents of a child with a disability. There is cold water fear. They do not always have the necessary knowledge and skills to talk to these parents. Professionals from the regular sector are afraid that the conversation will lead to questions related to the disability, which they have no answer to.

Centrum voor menselijke erfelijkheid

A centre for human heredity investigates the genetic nature of genetic diseases and congenital defects. You can go there for advice, discussion of research results and psychosocial support after making a diagnosis.

The following 4 centres are active in Flanders:

- Centre Medical Genetics Antwerp
- Centre for Medical Genetics in Brussels
- Centre for Medical Genetics Ghent
- Centre for human heredity in Leuven

Psychosocial assistance[35]

For psychosocial support there is the CKG (Centre for childcare and family support) and the CGG (Centre for mental health care).

- CKG (Centre for childcare and family support)
  The CKGs are recognized and subsidized by Kind & Gezin. They want to offer care to children aged 0-12 years. Families with a request for help can go there for guidance. In addition, they offer pedagogical home support for these families.[36]
- CGG (Centre for mental health care)
  This is a second line service where parents can turn to for various problems. Parents can go here for psychological counselling. This service can support parents of premature children and help with processing.[37]

Home guidance[38]

There are services for home counselling in the context of care for people with disabilities and in the context of special youth care. A home counselling service within the Flemish Agency for Persons with Disabilities provides educational assistance and

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[34] Analyse van de behoeften aan en het gebruik van opvoedingsondersteuning door ouders van een kind met een specifieke zorgbehoefte, Promotor: Prof. dr. Bea Maes, Prof. dr. Karla Van Leeuwen, Prof. dr. Johan Vanderfaeillie, Onderzoekers: Kristien Hermano s, 2016, https://steunpuntwvg.be/images/rapporten-en-werknotas/opvoedingsondersteuning-handicap

[35] Ouders van vroeggeboren kinderen: Beleving van de psychosociale begeleiding in het eerste levEnsjaar. Masterproef ingediend tot het behalen van de graad van master in de pedagogische wetEnschappen, optie orthopedagogiek door Evy Rathé, 2008.

[36] Website geraadpleegd op 2 mei 2018, op http://www.ckg.be

[37] Website geraadpleegd op 2 mei april 2018, op http://www.CGG.be

[38] Analyse van de behoeften aan en het gebruik van opvoedingsondersteuning door ouders van een kind met een specifieke zorgbehoefte, Promotor: Prof. dr. Bea Maes, Prof. dr. Karla Van Leeuwen, Prof. dr. Johan Vanderfaeillie, Onderzoekers: Kristien Hermano s, 2016, https://steunpuntwvg.be/images/rapporten-en-werknotas/opvoedingsondersteuning-handicap

general support to families with a child with a disability. Families with children with severe indications for the development of a disability are also accompanied.

Each service is aimed at one or more specific target groups. Every family has a permanent home supervisor, who usually comes to people's homes. Guidance parents can also be engaged in the guidance. Visit parents are themselves parents of a person with a disability.
The task of home counselling services is to support the development of children and young people with disabilities and provide pedagogical and psychosocial support for the parents and the wider context of these children.[39]. They do this in the form of ambulant or mobile individual support, outpatient or mobile outreach and group support. In terms of content, the guidance can lie in different areas. First of all, home supervisors provide parents with information about the disability and possibilities of their child, about forms of education, therapy and support, about practical or administrative matters, eto c. In addition, they closely follow the development of the child. On the basis of observations, they examine where the child stands in various development domains and give advice to parents about how the development of the child can be stimulated. Parents also receive advice on the education of their child. By getting to know the pedagogical question of the child better and by acquiring specific parenting skills, they can better tailor the parent-child interactions and daily life situations to the needs of their child. Home counsellors support both parents and other family members in processing and dealing with the disability of a family member. Finally, home carers also form the link between the family and other services or care providers. For example, one goes in search of suitable childcare, education or daytime activities for the child.

Midwives
Midwives indicate that they are faced with ethical questions. While trying to promote pregnancy as a normal occurrence, there is a contradiction with the routinely offered first trimester screening where one is focused on establishing deviations[40]. Just offering a screening test, which implies that something could be wrong, can cause unnecessary anxiety in the parents [41].

Midwives also point out that a phase of 'conditional' pregnancy is built in by prenatal screening and diagnosis. As long as the couple awaits the results of the test, they dare not really attach themselves to the child and experience the pregnancy as such.[42].

Midwives feel insecure when they are involved in communicating with parents about the results of prenatal diagnosis [43]. Especially the communication with parents who

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[39] Maes, B., NoEns, I., & Heyndrickx, T. (2015). Zorg en ondersteuning voor kinderen en jongeren met een handicap. In: J. Vanderfaeillie & B. Maes (Red.), Handboek jeugdhulpverlening. Deel 2. Nieuwe ontwikkelingen in het zorgveld (pp. 219-259). Leuven: Acco.

[40] Williams, C., Alderson, P., & B. Farsides, Dilemmas Encountered by health Practitioners Offering Nuchal Trano slucency Screening. A Qualitative Case Study, Prenatal Diagnosis 22 (2002) 216-220.

[41] Ekelin, M. & E. Crang-Svalenius, Midwives' Attitudes tand Knowledge about a Newly Introduced Foetal Screening Method. Scandinavian Journal of Caring Sciences 18 (2004) 287-293.

[42] Katz Rothman, B., Spoiling the Pregnancy. Prenatal Diagnosis in the Netherlands. In: R. De Vries, C. Benoit, E. Van Teijlingen (eds.) Birth by Design. Pregnancy, Maternity Care and Midwifery in North America and Europe, Routledge, New York, 2001, 180-200.

[43] Fairgrieve, S., Magnay, D., White, I. & J. Burn, Maternal Serum Screening for Down's Syndrome. A Survey of Midwives' Views, Public Health 111 (1997) 383- 385.

were in no way prepared for the fact that something could be wrong, is experienced as very stressful [44].

Midwives do not know well how to prepare such parents adequately. They warn that inadequate counselling of the parents can give rise to uncontrolled anxiety reactions after hearing the abnormal results.[45]. Adequate counselling requires more time than what is provided in the healthcare practice today.

Midwives consider it important that they understand the ethical views, fears and hopes of women undergoing prenatal diagnosis[46]. Midwives need opportunities to express their feelings and opinions about prenatal diagnosis [47,48]. These possibilities for exchanging feelings and opinions are necessary to stand up in the confrontation with complex and stressful situations.

Midwives also feel a need for continuing education[49]. Midwives express their concern about the evolution that is taking place in our society and more specifically about the way we think about people with a disability. Midwives therefore want to be involved in the debate on the ethical and social aspects of prenatal diagnosis and termination of pregnancy.

Counselling as teamwork

Good counselling regarding prenatal diagnosis, also in its screening dimension, can not be realized by one person. It is therefore recommended that couples who receive or consider prenatal diagnosis, and of course those who undergo it, should be accompanied by a multidisciplinary counselling team: the gynaecologist is assisted by a midwife, a psychologist, a clinical ethicist, a social assistant or a social nurse. The counselling team enters into a partnership with a centre for human heredity to which clinical genetic counsellors are connected.

It is emphasized that the midwives have to be involved in the counselling process right from the start and therefore cannot simply be confronted with the results afterwards. They should also be involved in the development of the ethical institutional policy on prenatal diagnosis.

Phases of the care process around prenatal diagnosis

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[44] Williams, C., Alderson, P., & B. Farsides, Dilemmas Encountered by health Practitioners Offering Nuchal Trano slucency Screening. A Qualitative Case Study, Prenatal Diagnosis 22 (2002) 216-220.

[45] Garel, M., S. Gosme-Seguret, M. Kamino ski & M. Cuttini, Ethical Decision-making in Prenatal Diagnosis and Termination of Pregnancy. A Qualitative Survey Among Physiciano s and Midwifes, Prenatal Diagnosis 22 (2002) 811-817.

[46] Jallinoja, P., Santalahti, P., Toiviainen, H. & E. Hemmininki, Acceptance of Screening and Abortion for Down Syndrome Among Finnish Midwives and Public Health Nurses, Prenatal Diagnosis 19 (1999) 1015-1022.

[47] Ryder, I., Prenatal Screening for Down Syndrome. A Dilemma for the Uno supported Midwife?, Midwifery 15 (1999) 16-23.

[48] Garel, M., S. Gosme-Seguret, M. Kamino ski & M. Cuttini, Ethical Decision-making in Prenatal Diagnosis and Termination of Pregnancy. A Qualitative Survey Among Physiciano s and Midwifes, Prenatal Diagnosis 22 (2002) 811-817.

[49] Ekelin, M. & E. Crang-Svalenius, Midwives' Attitudes tand Knowledge about a Newly Introduced Foetal Screening Method. Scandinavian Journal of Caring Sciences 18 (2004) 287-293.

A careful and dignified framework of the care process for prenatal diagnosis is very important. Here we follow the recommendations formulated in the work of Carl Loots[50].

- Counselling before pregnancy
  Because of the drastic nature and the possible consequences of prenatal screening and prenatal diagnosis, careful counselling will ideally start before pregnancy, especially if there are risk factors known to cause birth defects. For specialist guidance, a referral to a centre for human heredity may be appropriate.

- Offering prenatal diagnosis
  When a screening test is offered to pregnant couples, it is of the utmost importance that they are well informed. It is recommended that the parents receive this information well before the screening test so that they can quietly think about the discussed and, if necessary, obtain additional information. This should include: the purpose of the test, the predictive nature of the test, the actual procedure and the further course of the research, the risks associated with the test and the chance of false-positive and false-negative results. The significance of the implications for the couple must also be explicitly discussed. In addition to the information provision, each test must be preceded by an explicit consent from the pregnant woman.

  In case of a deviant screening result, parents must be well informed about the diagnostic method that is designated as such in their situation. The possible continuation of the diagnostic procedure can also be discussed. Parents also need to know that it is not possible to detect all disorders preventatively via prenatal diagnosis. Time is allocated to inform about the condition that will be tested: symptoms, complications, prognosis. Parents must also be informed that, even if there is certainty about the diagnosis, there is often no great certainty about the seriousness of the abnormality, about the specific handicaps, about the treatability and about the burden on the child and for themselves. . Parents also need to be asked about the knowledge and experience of congenital abnormalities in general and the deviation to which one is at risk in particular; the family situation; how planned and desired the current pregnancy is; the perceived or already experienced capacity to deal with stress and adversity, which strategies (coping) are used for this (support from partner, family, friends, moral attitudes, religion, etc.); their opinion about the life of and with a handicapped child, whether they will be able to cope with the upbringing of a handicapped child; or opt for abortion before. This extensive informative dialogue should support parents in making a responsible assessment of whether or not to proceed to prenatal diagnosis. Giving permission for the prenatal diagnostic test then takes the form of an 'informed decision-making process' ino stead of merely 'informed consent'.

- Notifying normal research results
  The time between the test and the communication of the results is often unbearable for the parents. Before the procedure is started, the parents must also be informed about the time necessary for further research, such as results of a

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[50] Carl Loots (2001)

cell culture. Moreover, clear agreements must be made in advance about how, where and when the research results will be communicated. Normal research results must also be communicated as quickly as possible. It must always be borne in mind that normal research results do not imply the birth of a (perfectly) healthy child.

- Notifying deviant research results
    - *Notifying abnormal screening results*
      The result of the non-invasive screening tests is communicated to the parents in the form of a risk calculation. It takes a lot of emotional work to use the given risk in your own life. It is therefore important that parents receive reference points to interpret the result. After all, on the basis of this risk, invasive research will or will not be carried out. Preferably, the follow-up of the diagnostic procedure with the parents will be discussed before the screening. Although the screening tests are considered to be non-invasive, they in fact strongly affect the pregnancy trajectory[51].
    - *Notifying abnormal diagnostic results*
      When it is established after diagnosis that the unborn baby is suffering from a genetic disorder or when clear anomalies are visible on the expertise echoes, this is a serious blow to the parents. Conducting bad news talks must be done with the necessary care. An appointment must be made for an extensive discussion with both parents, which should take place as quickly as possible. It must be taken into account that human information processing is delayed with emotionally strong messages. Providing a written summary of the diagnosis and other important information can help the parents tread all the information at home. Availability of psycho-social support (psychologist, social nurse, ...) intra muros is recommended. The GP can also play an important role in the parents' processing process. It is advisable to involve the midwife from an early stage in the prenatal diagnosis care process. Midwives can play an important role in repeatedly explaining information to parents, in psycho-social counselling and in creating a caring atmosphere. In addition, it is desirable that after the adoption of a derogation, parents are given the opportunity to contact the relevant organ specialists as well as other people with experience, such as parents of children with disabilities, self-help groups, and son.

2.5.2 Bulgaria

On the maternity ward level parents and other members of the extended family (grandparents) of newborns with disabilities and complex needs receive psychological support service by a clinical psychologist. The main objectives of the first consultation are:

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[51] Geelen, E. et al., Opgelucht, maar ook aangedaan. Ervaringen van vrouwen met risicoschattende testen in de zwangerschap, ZonMw, Maastricht, 2004.

- Support in structuring and selecting the information that the family needs (sometimes parents are highly anxious, and this prevents them from asking important questions when meeting with the professionals responsible for the health of their baby);
- Preparation of an initial action plan (better understanding of the baby's disabilities, opportunities for further development);
- Encouraging the active connection of the mother with the baby;
- Encouraging mother's competence (eg: "No one knows your child better than yourself").
- Counseling the family about the possibilities for psychological support after leaving the hospital (connection with institutions that help children with disabilities, individual and family therapies).

After discharging from the hospital of the mother and the baby, parents and other family members may receive various services related to the psychosocial support by Early Intervention team or Family counseling centres for children with disabilities aged 0-3. Child protection departments under Ministry of Labour and Social policy also provide psychosocial support of the families of babies with disabilities and complex needs by directing them and providing them with access to various social services in the community.

2.5.3 Romania

Psychological support is almost non-existent in hospitals. There are very few hospital psychologists (for example, in oncology there is on psychologist for 70 patients), who have to deal with evaluations, and have very little time to advise patients.

Also, at the hospital level, for situations when parents find out that their child has a disability or is in a rather serious medical condition (prematurity, other complications), there is no protocol that offers, through the psychologist, support or counseling.

Psychological support is also lacking in Pediatric Neurology Clinics, where the neurologist is the one who discovers the diagnosis and communicates it to the parents, and there is no further follow-up to the evolution.

In providing psychological support, it should not be forgotten that all these congenital abnormalities or the problems of prematurity affect, in the long run, not only the diagnosed child, but the whole family, all of whom need support for a long time.

2.5.4 Turkey

Psychosocial support is not given to parents unless the family requests.

2.5.5 Conclusion

Psychosocial support is very limited and vary from country to country in EU.

2.6 State/public/NGO (legal and financial) support of babies with disabilities and complex needs and their parents

2.6.1 Flanders (Belgium)

In a centre for developmental disorders (COS) mainly very young children are examined with a risk of or a suspicion of problems in the development.

Each research project carried out by a COS consists of several studies. Depending on the question and the information already available about the child, the examination is carried out by a doctor, a psychologist, a physiotherapist, an occupational therapist or a speech therapist.

A COS provides independent advice and orientates the child and its parents to the most suitable aid offer. This can be both in the regular supply (reception, school) and in the specialized offer (a provision of the VAPH, a service within the mental health care, a private service ...). A COS does not offer guidance or treatment itself.

The VAPH offers the following support:

- Directly accessible help (RTH) is limited, disability-specific support in the form of counselling, day care or accommodation for those who need help from time to time. For direct accessible assistance, no application must be submitted to the VAPH. One goes directly to the healthcare provider.
- The VAPH provides grants for aids and adjustments. The VAPH can also be contacted for assistance dogs, incontinence aids and pedagogical assistance with higher studies. An allowance for resources and adjustments must be requested.
- A personal assistance budget (PAB) is a budget that the VAPH gives to the parent (s) to organize and finance the assistance for their child at home or at school. With the personal assistance budget you recruit assistants and you become an employer.
- A multifunctional centre (MFC) is aimed at people with disabilities up t21 years (exceptionally extendable up to and including 25 years) who need specific support. A multifunctional centre offers guidance, day care, and accommodation. A number of specialized centres also offer diagnostics and intensive treatment. Support for a multifunctional centre requires a youth assistance decision from the intersectoral portal of the youth welfare agency.
- For students with a disability Who are enrolled in mainstream education, the VAPH can, under certain conditions, provide compensation for transport and accommodation costs.

2.6.2 Bulgaria

2.6.2.1. State support:

Social support to persons with disabilities is ensured through the provision of various types of resources - benefits, allowances, pensions, services and social security, social assistance, employment law, health and safety, as well as a number of tax and financial incentives. (National strategy for persons with disabilities 2016-2020)

- **Financial**

Families of newborns with disabilities receive **one-off** family allowances:

1. One-off benefit upon childbirth;

2. If permanent disabilities of 50% or more are established by the time the child reaches the age of 2, the mother shall be paid an additional one-off benefit to an amount fixed annually with the State Budget of the Republic of Bulgaria Act for the respective year, but not smaller than in the previous year.

3. People with permanent disabilities, according to their necessities shall have the right of earmarked allowances and relief for:

a. purchase and adaptation of personal vehicle and adaptation of a parking place;

b. import of personal vehicle;

c. reconstruction of the home;

d. attendants for persons with impaired sight, persons with impaired movement and interpreters for persons with impaired hearing

4. People with disabilities, according to their necessities, shall have the right of earmarked allowances and relief for purchase and repair of technical supportive devices, facilities and appliances for compensation of the disability.

5. The municipalities should provide houses from the municipal housing funds to people with permanent disabilities under the terms and conditions of the Law on the municipal property

Monthly family allowances:

1. Monthly allowance for children with permanent disabilities below 18 years of age and prior to finishing secondary school, but not later than reaching the age of 20 – when the child reaches the age of 18 years, and if it is in school – when it graduates from high school but not after it reaches the age of 20 years.

2. The monthly benefit for a child with a permanent disability, established by the competent health authorities, shall be paid regardless of the income of the family, and when the total amount of benefits for the family is determined, the amount of the benefit for the child with permanent disability may not be lower than 2 times the amount of the benefit for a family with one child.

3. People with permanent disabilities have the right of monthly allowance for social integration according to the kind and the level of disability and their personal necessities (transport services, information and telecommunication services; education, spa recreation and rehabilitation services, healthy diets and medicines, accessible information, satisfying other basic living necessities)

Social services:

According to a research conducted by For Our Children Foundation and Open Society Foundation – Bulgaria, although the number of social services for children to increase during the last decade, still there is lack of purposive policy in the field of social support for children aged between 0-7 and their parents, lack of legal regulation, standards, methodology, application rules, licensing of the provider, requirements to training of the professionals in the field, etc. Social services might be financed by the State Budget as activities delegated by the State, by the municipal budgets as local activities, as well as under various projects on national and international programmes and self-financed, in case they are provided by registered private suppliers.

Only a few services are available for children with special needs from 0 to 3 years in Bulgaria and the support they provide is based on medical models of care.

- **Homes for medico-social care for children** – are medical establishments under the Medical Establishments Act – legal entities, financed by the state budget for their specific functions, second level budget spending units at the Minister of Health. Children aged 0-3 are placed there and if they have moderate or severe physical disabilities, they can stay in the HMSCC after reaching the age of 3. Children are placed in HMSCC by an administrative order of the Directorate for Social Assistance and a subsequent court ruling of the District Court at the location of the child. According to the rules and regulations of DMSGDs children with low weight due to prematurity can also be placed there for treatment.[52]
  As of 2017 there were 16 HMSC for children in Bulgaria with total capacity of 1 034. The entrants for the same year are 713 children, as the majority of them are under age of 1 (619).[53] The number of the institutions and the children accommodated there decrease each year since 2011, because the Bulgarian social authorities in partnership with NGOs working in the field of child protection prosecute long-lasting reformation of these institutions as part of the concept for deinstitutionalisation of children in BG. Deinstitutionalization in Bulgaria has to be understood as a bilateral process - both closing and reshaping of the existing institutions and opening services in the community, which shall serve as an alternative of the institutional care.[54] This type of institutions should be closed down till 2020.
- **Complexes for integrated health and social services for children from 0-7 years** – the Complexes provide services supporting families expecting a child and families with young children with and without disabilities. Services are based on the different target groups needs and are divided as follows: services for future parents, services for parents and services to families with children up to 3 years. The services provided to parents of children up to age of 3 and to children themselves are focused on the development of the parenting skills. The services provided to the future parents and those with infants are mainly carried out via mobile social work and social services in specially equipped community centres. Mobile work aims to support parents in meeting their child's needs and to overcome the challenges of their living environment. The services provided outside the child's home, aim to build a safety space that meet their needs. The services provided to children aged between 3 and 7, are aimed at their integration in kindergartens' setting and improvement of their school readiness.
- **Centres for Maternal and Child Healthcare for children with disabilities aged 0-3 years** – Centres for Maternal and Child Healthcare are specialised structures, part of the national healthcare system which provide outpatient care for pregnant women, mothers and children up to 3 years of age. Centres are established as independent units, part of existing outpatient care facilities. The Centres provide regional health-information, health-training, health-advisory, coordinating and guiding services for pregnant women, mothers and children up

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[52] UNICEF Bulgaria - Terms of reference for consultants to assess the approaches for closure of infant homes in BG

[53] Bulgarian Statistical Institute

[54] Bulgarian National strategy for long-term care

to 3 years in order to improve the outpatient care of these groups. Health services are provided by qualified nurses / midwives and the families can be supported also in their homes. The long-term goal of these centres is to contribute to the improvement of some key health and early child development indicators by promoting and supporting good parenting practices, health promoting and facilitating access to health and social services. The team of the Centre includes: paediatrician, nurse, midwife, psychologist, social worker and speech pathologist.

- **Daily care centres for children with disabilities aged 0-3** – The Centres provide social services to children up to 3 years old with physical, sensory and / or mental disabilities who need daily rehabilitation, physiotherapy and psychotherapeutic support. The support of the children might be provided full-time or part-time according to their individual needs. The team of the DCCs is comprised by physiotherapist, physical rehabilitation specialist, nurse, psychologist, speech therapist. For the improvement of the physical, intellectual and emotional state and development of the children with disabilities, DCCs provides physiotherapy, rehabilitation, psychological support, language and speech therapy, art and music therapies. Some of these services are also available for children's families.
- **"Mother and baby" Units -** The Units provides temporary shelter for pregnant women and mothers of children up to 6 months of age who are at risk of abandoning their child.
  The main activities of the Units are:
    - provision of temporary shelter for the parent-child couple or pregnant woman in conditions of security and respect for dignity;
    - psychosocial support (mediation to improve relationships and relationships in the family, with the baby's father, mothers' parents, extended family, supportive environment, etc.);
    - foster parent-child relationship;
    - assisting in acquiring and strengthening skills for independent living;
    - parenting skills and baby care training;
    - social and legal services - counselling, guidance and information.
- **Early Intervention teams** – The EI service is aimed at babies and young children from 0 to 3 years of age who:

- are at risk of lagging behind in their development
- are premature babies or babies with low birth weight
- are lagging behind in one of the developmental areas - cognitive, motor, speech, social, emotional
- have been diagnosed with disability or chronic disease

EI consultants provide home visits and help parents to understand more about their child's needs and how to promote his development. Consultants together with the parents plan the activities that suit best the needs of the child and the family.
The Early Intervention team includes a physical rehabilitation specialist, speech therapists, special pedagogues, psychologist, paediatrician, social worker and breastfeeding consultants.
For more information, please see the dedicated section in this report.

2.6.3 Romania

At ward level we encounter:

- **The Unu şi Unu Association**

- In three 3rd degree maternities in Bucharest - Cantacuzino, Giulești (Panait Sârbu Clinic Hospital) and St. Pantelimon and one in Timişoara – the Unu şi Unu Association organizes once a week a support group for mothers with premature or intensive care hospitalized babies and offers kinesiotherapy for babies who are still premature when they leave the intensive care unit. Starting with the spring of 2018, the Association added a new component to the project - the ATTEK method - auditory-tactile communication between parent and child

- Also, the Unu si Unu Association completed the planning and endowment of the first sensory neonatal post-therapy room in Romania at the Panait Sârbu maternity hospital in Bucharest.

- At the moment the Association tries to implement the concept and principles of Family Center Care, in 2 maternities in Bucharest

- **Inima Copiilor**

- In the Marie Curie Children's Hospital, in 2018, they have launched a program that aims, with the help of trained volunteers, to take care of abandoned children or those whose parents rarely visit, from the intensive care unit (1 out of 5 children in the department is in this situation).

- The lactation counseling of mothers with children admitted to the newborn intensive care unit of the "Marie Curie" Emergency Hospital for Children is a volunteer project of the Association of Lactation Consultants in Romania, which aims to provide information from certified specialists in the field (usually IBCLC certified international lactation consultants), every week.

- A milk collection system has been created, the milk ends up in the Milk Bank, but the current legislation does not allow its use yet, which leads to an absurd situation where the stored milk is thrown away.

- **Salvaţi copiii România**

- they have been particularly involved in raising the necessary funds for endowment of children's hospitals and intensive care units within maternities with medical equipment (76 maternity hospitals from 38 counties, with 380 equipment items, worth of over 3 million Euro)

- Another project is a breastfeeding brochure, from the ABC collection- let's learn about children, found on the Association's website and in some maternity wards

The government provides support only after establishing the child's diagnosis and fitting it into a degree of disability - as detailed above.

Outside Maternities:
In practice, there are many NGOs specializing in a certain type of disability (epilepsy, cerebral palsy, down, autism etc.) compensating the lack of government's involvement in the recovery of children with disabilities, providing parents in exchange of a fee or free of charge, depending on the funds - specialists, recovery plans, space and equipment needed for the recovery of children.
For parents, these NGOs provide informative materials and organize support groups.

2.6.4 Turkey

State legal support:

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 Ministry of Family and Social Policy carry out the work necessary for the standardization, development and dissemination of support and maintenance services.

- 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 (early retirement, free permission etc.) 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 cardholders 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, and 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.

2.6.5 Conclusion

Every country in Europe aims to develop disability-oriented services in line with its economic social opportunities and laws. But there is no common denominator in this regard between countries. Legal and financial support from states and NGOs are different between countries.

2.7 Existing educational/ training programmes for medical staff working ...

2.7.1 In gynaecology and fertilization clinics related to communication and interaction with families that discover at neonatal screening that have a baby at risk to have disabilities or that could be born prematurely

2.7.1.1 Flanders (Belgium)

There is no evidence of existing training on this subject, but there are recommendations. These are brought together below.

"Without no selfish humanity, the future of handicapped unborn life is hardly guaranteed. That higher form of love presupposes more than ethical reason and sense. The source of this lies in an inspired or non-religious inspiration of a person who is willing to give his own life for the good of others " (Van Neste 2007)[55].

Prenatal research indicates (possible) disability in babies [56]

Parents often characterize counselling for prenatal screening and diagnosis as short, technical and businesslike. On the one hand they value the atmosphere of objectivity in which counselling takes place, but on the other hand they feel disappointed when they experience that they cannot go to the gynaecologist with their doubts and their deeper

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[55] Van Neste, F., Een hogere vorm van liefde. Zorg voor het gehandicapte ongeboren leven, Terti27 juni 2007, 3-4.

[56] Het zorgproces rond prenatale diagnostiek, http://www.standaard.be/extra/pdf/advies12.pdf

questions. The standard answer 'It is your choice' without extensive guidance is experienced as very negative. Parents generally find it very desirable that the counsellor takes sufficient time and that he tries to understand the parents as well as possible. Parents also find it very important to hear the opinion of an expert after hearing different results, before making a decision. The parents attach great importance to the oral and written information they receive from the care provider. However, the emotional state of the parents does not always enable them to adequately understand the information or task specific questions. Moreover, it appears that after receiving the results of risk-related tests, parents still have a lot of interpretation work to make results manageable and to make decisions about whether or not to proceed with invasive research. The parents indicate that connecting consequences to the results of screening research requires more explanation than merely communicating one result 'good' or 'not good'. Dealing with screening results implies not only understanding and interpreting the given risk percentages, but also giving meaning to these data in one's own life. Parents who have an increased risk of children with a congenital abnormality or Who are concerned on other grounds about (the health of) their children often only dare to start a pregnancy because the possibility of prenatal diagnosis exists. Nevertheless, prenatal diagnosis is not only experienced as a reassuring possibility. There are often mixed feelings. The most frequent emotion that parents experience during consultations related to prenatal diagnosis is fear. This fear has to do with the fact that parents at least want to avoid miscarriage. Moreover, one risks ending up in a situation in which one must consider aborting the pregnancy. Finally, parents are worried about the social evolution that makes it increasingly difficult to accept disabled life. Some parents feel complicit in this evolution by using the possibilities of prenatal diagnostics themselves.

In the care process concerning prenatal diagnosis, one has to make choices about what is considered valuable and human worth in life; these are choices of moral nature. As a result, the care process surrounding prenatal diagnosis can itself be regarded as a moral practice. The choices that parents must make should not only be expressed in medical or psychological terms, but should also be presented as choices with a moral impact. In other words, they have to decide what is right for them to do (for example 'respect for autonomy', 'quality of life'). Dosed medical information and psychological counselling provide necessary but insufficient conditions for achieving an integrated care process for prenatal diagnosis. Recognizing the moral dimension of the choice process, together with the provision of the necessary medical information and psychological counselling, enables parents and care providers to better understand the full scope of the selection process.

Good counselling regarding prenatal diagnosis, Also in its screening dimension, can not be realized by one person. It is therefore recommended that couples who receive or consider prenatal diagnosis, and of course those who undergo it, should be accompanied by a multidisciplinary counselling team: the gynaecologist is assisted by a midwife, a psychologist, a clinical ethicist, a social assistant or a social nurse . The counselling team enters into a partnership with a centre for human heredity to which clinical genetic counsellors are connected. The midwives have to be involved in the counselling process right from the start and cannot simply be confronted with the results afterwards. They should also be involved in the development of the ethical institutional policy on prenatal diagnosis.

The decision to interrupt the pregnancy after prenatal examination [57]

The termination of a pregnancy of a desired child is a radical event that has a major impact on the parents involved. Hospitals therefore need to pay a lot of attention to good care and aftercare when breaking off a pregnancy.

The attending gynaecologist, together with the head midwife, must give a clear explanation of how the termination of pregnancy will take place, how much time this intervention requires and what physical and emotional impact the parents may expect. This can for example be supported in writing via an informative text. The profound existential experience to which the woman in particular is exposed as a mother needs special attention. The gynaecologist and the head midwife also discuss with the parents whether they want to see the foetus, and whether or not they want to give it a name.

If the parents wish a personal farewell, agreements are made in consultation with the pastoral service in connection with funeral and farewell rituals. This can help the parents in completing the grieving process. The gynaecologist consults in time with the head midwife on how the termination of pregnancy can be fitted into the work schedule, and how optimal professional guidance can be Ensured. The midwife who will assist with the termination will be informed well in advance. She presents herself to the parents as the person who will accompany them during the termination of pregnancy. An adapted room will be placed on the maternity reserved where the woman will stay during her stay (without playpen, without monitoring, etc.). If the parents agree, the pastoral service is informed and asked to be available.

Parents must decide for themselves whether to communicate their decision to terminate the pregnancy to relatives, friends or acquaintances. The midwife and the pastoral service support the parents in making choices and offer concrete examples to them. Particular care must be given to other family members (other children, grandparents, ...) who each also go through a grieving process.

After the farewell of the baby, the dismissal is followed by an accompanying conversation with the gynaecologist, the head midwife and the pastor. Three days after discharge, the parents are contacted and they are asked whether or not they want to make an appointment to come by. After two weeks, a first exploratory meeting will take place with the gynaecologist, where possible results of autopsy and other possible tests will be discussed. It is recommended to contact the parents after about six to eight weeks so that they can express their experiences and feelings. It is also advisable to make an appointment around the period that the delivery would normally take place.

Need for a multidisciplinary approach

Because of the interwovenness of gynaecological, genetic and midwifery aspects in the care process of prenatal diagnosis and termination of pregnancy, it is essential that gynaecologists, geneticists, midwives and other care providers (psychologists, social workers, general practitioners, pastors, ethicists) respect each other's contribution tan close cooperative relationship.

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[57] Het zorgproces inzake zwangerschapsafbreking na prenatale diagnostiek, http://www.standaard.be/extra/pdf/advies13.pdf

2.7.1.2 Bulgaria

Trainings on communication and interaction with patients are not part of the university educational programmes for medical doctors, midwifes and nurses, but are provided as continuing education in the most of the medical universities and the bigger hospitals in Bulgaria. Below you will find a table including most of the current trainings related to the communication and interaction with patients.

Formal education:

Course type	Course name	Target group	Duration	Training provider
Continuing education/ Postgraduate qualification	Psycho-social communication in nursing practice	Nurses and midwifes	2 days	University of Ruse
Continuing education/ Postgraduate qualification	Communication skills of the physician. Working with children and adults	General practitioners	3 days	Diagnostic & Consultation Centre "St. Marina"- Varna
Continuing education/ Postgraduate qualification	Family and social environment of the newborn	Doctors, midwives, nurses, rehabilitators, physiotherapists	3 days	Diagnostic & Consultation Centre "St. Marina"- Varna
Continuing education/ Postgraduate qualification	Early childhood intervention	Midwives, nurses, rehabilitators, physiotherapists	6 days	Medical University of Varna
Continuing education/ Postgraduate qualification	Supporting the family to promote the early childhood development	Medical specialists	2 days	Medical University of Varna
Continuing education/ Postgraduate qualification	Training in communication skills	Medical doctors	2 days	Medical University of Pleven
Professional training	Training in communication skills for doctors	Medical doctors	3 days	Military Medical Academy - Sofia
Work based training	Communication skills in the work with patients	Medical doctors from the Military Medical Academy - Sofia	3 days	Military Medical Academy - Sofia
Continuing education	Influence of the psychological changes in young mothers on communication with midwives	Health Care professionals	1 day	First specialized obstetrics and gynaecology hospital for active treatment "St. Sofia" - Sofia
Continuing education	Medico-social, pedagogical and psychological	Health Care professionals	5 days	Medical University of Sofia

	aspects of the "patient-medical team". relationship			
Continuing education	Psychotherapeutic Approaches in Medical Practice	Health Care professionals	5 days	Medical University of Sofia

2.7.1.3 Romania

There is no evidence of training on this subject.

2.7.1.4 Turkey

There is no constructed program.

2.7.1.5 Conclusion

In some countries there are training programs and daily seminars for medical specialists to develop communication and interactions with the family while others are lacking. Because of this, there is no common program.

2.7.2 On the maternity ward level related to communication and interaction with families of newborns with disabilities and complex needs (discovered after birth)

2.7.2.1 Flanders (Belgium)

Following advice is given to neonatology units (NIZ / NICU and N*)[58]:

- Provide education for caregivers around the needs of parents.
    - Involve experiential expert parents in education.
        - Role play, discussion groups, story
- Ensure an environment that is emotionally safe and supportive and that creates confidence.
- Language use
- NIZ / NICU and N* design
    - Ensure that parents can be with their baby continuously.
    - Provide clear, honest information to parents with the necessary empathy.
- Communication training
    - Make decisions about caring for the baby in consultation with parents.
    - Provide individualized family-oriented care.
- Recognizing body language
    - Help and support parents in caring for their child.
- Respect and empowerment of parenting[59]
- From paternalism to care in partnership, coaching
- Set up parent groups.

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[58] Bron: UZ Leuven, https://www.uzleuven.be/sites/default/files/Neonatologie/Van%20ontwikkelingsgerichte%20zorg%20tot%20familie%20ge%C3%AFntegreerde%20zorg_Christine%20Vanhole.pdf

[59] Creating Opportunities for Parent Empowerment - COPE – Melnyk et al.(2006

To support the family, the following advice is given:

- Psychological and emotional support
- Information and education
- Possibility to be with the baby day in and day out
- Parents are partners in healthcare and have a say in decisions
- Parents are present at the hall round
- Support when the child is transported from the regional centre
- Photos
- Guidance and reception
- Support for breast feeding
- Encouragement of kangaroo care
- Activities / attentions in support of parents
- Parental support to parents
- Preparation for discharge and departure home
- Well-founded palliative care
- Support for loss and grief, taking into account cultural and ethnic differences
- Support in socio-economically difficult situations
- Parental Advisory Council
- Educational parents' sessions
  - Psychological and emotional impact of preterm birth / illness
  - Recognizing baby's signals
  - Breastfeeding in premature birth
  - Preparing for dismissal
- Individual contacts psychologist / child psychiatrist / social worker
- Regular consultation psychosocial framework

At the same time it is recognized that there are several obstacles:

- Organizational
  - Training-related
    - Inadequate training: specialized knowledge, communication skills, dealing with emotions
    - No adjusted selection system for student nurses
    - Lack of professionalism
  - Clinical factors
    - Difficult working conditions: lack of time, workload
    - Lack of further training and evaluation
    - Top-down policy - authoritarian
    - Lack of communication among colleagues
- Family related
  - Diverse and difficult coping with the baby's medical condition
  - Socio-cultural differences
  - Economic aspects
- Nursing wise
  - Psychic
  - Physical
  - Sociocultural

2.7.2.2 Bulgaria

2.7.2.3 Romania

There is no evidence of training on this subject.

2.7.2.4 Turkey

Generally gynecologists or newborn doctor gives the information. There is no specialized educational/training program for that.

2.7.2.5 Conclusion

Generally, gynecologists or newborn doctor gives the information. There is no specialized educational/training program for that in every country.
In situations where postnatal disability is understood, different approaches are used in each country in order to explain the situation to the family, to give information about the baby and to plan the future. This process is managed by a gynecologist. Specialists in contact with parents do not have special training in communication and approach to parents, except for a few lessons they have taken during their undergraduate and specialist training.

3 Availability (or not) of early intervention team and / or team working with disabled newborn babies

3.1 Flanders (Belgium)

Ja. Zie hierboven (COS, Kind & Gezin).

3.2 Bulgaria

Since 2008 early intervention services are established in the districts: **Sofia, Pleven, Varna, Burgas, Ruse, Stara Zagora, Plovdiv, Pazardzhik, Dobrich, Vidin**. Up to 2015 there are 47 EIC providing services to children up to 3 years old. Ones of the biggest early intervention cervices providers in BG are Karin Dom Varna and For Our Children Foundation.

According to the definition of Karin Dom, EI service is "*transdisciplinary, coordinated service that supports families of infants and young children up to 3 years of developmental concerns. It aims to improve the child's development and family life, as well as to prevent the abandonment of children born with disabilities*."[60]

The EIC model applied by Karin Dom is used as a core model by the other EI centres in Bulgaria and they have been trained on it by the Foundation.

According to the EI programme's methodology developed by Karin Dom and For Our Children foundations Early Intervention Programme (EIP) is "a new model of services, provided in the natural environment of the child, and based on partnership and family-centred approach. This model of early intervention works to support and strengthen parent capacity as well as child outcomes and provides parents decided to abandon their child with alternative to institutionalisation forms of support."[61]

The EIC programme includes:

- home visits
- parent-toddler play groups
- family support network
- breastfeeding support.

The Programme provides services to families of children aged 0 to 4, who are either with disability, delay in one or more of the developmental areas or are at risk of developmental delay (e.g. social factors, low birth weight, etc.). Through early assessment combined with active intervention, EIP increases the chances of children to participate in inclusive mainstream educational settings. The Home Visitation Programme includes identification (e.g., screening); needs assessment; development of individualised service plans; delivery of specific interventions and regular monitoring of the child's progress. The specialists plan and implement interventions in partnership with the family by focusing on child's strengths. The EIP team comprises of a physiotherapist, speech therapist, psychologist, social worker, breastfeeding consultant and paediatrician.[62] Through a series of follow-up visits, the specialist gives practical demonstrations to the parents on how to teach their child various skills through play or such routine activities as dressing, eating, bathing, etc. The specialist considers the family's needs and beliefs, and builds on their strengths, knowledge, and skills. In

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[60] Karin Dom - Report 2016

[61] Ilieva, A., Vasileva, V., 2016, Prevention and early intervention services to address children at risk of poverty (Dublin, 18-19 February 2016), comments paper

[62] Ibid.

addition to these home visits, the specialists can also make visits to other natural environments, such as nurseries, kindergartens, playgrounds, etc.[63]

Children are being included in the Programme upon request of the parents. The usual practice is these requests to be submitted as a result of directedness by partners of the EI centres or when the parents have found information in Internet about the EI services and the providers. According to the internal statistics of Karin Dom the medical professionals are of highest percentage with regards to the directing towards the EI programme – 29%, while as 25 percentages of the requests are as a result of parent's initiative.

Early intervention teams also provide support at the maternity level for parents of babies with disabilities and premature babies or babies at risk of abandonment. The EI teams also support the medical professionals in the obstetrics and gynaecology departments in creation of the individual medico-social plans of the newborns with disabilities or at risk to acquire disabilities, including the premature babies.

The Bulgarian Early intervention system is now under research and observation by the director of the RISE institute (Washington)[64] by the request of the Bulgarian authorities and NGOs, and the findings from the research, as well as recommendations regarding the institutionalisation and further development of the programme will be presented in June 2018.

3.3 Romania

3.4 Turkey

It is necessary to prove the disability in order to benefit from the rights given to the disabled person by the laws. 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.

The reports of children with Cerebral Palsy generally involve participation in the 9following programs:

- Physical Disabilities Support Training Program
- Mentally Handicapped Support Training Program
- Language and Speech Disorders Support Training Program

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[63] Karin Dom Foundation - Early assessment coupled with early intervention

[64] http://www.riseinstitute.org

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

In all the hospitals (private or public) with neonatal intensive care unit, the nurse provides the support and care but there is no teamwork.

All the babies who have a diagnose for disability can get medical and rehabilitation services from governmental and /or non-governmental institutions but the quality of service in the whole country differs in each region.

For all the hospitals, for the babies who need early intervention there is a few university hospital, NGO and special center that has team members working with disabled newborn babies.

Gazi University, Hacettepe University, Marmara University, Dokuz Eylül University, Zeynep Kamil Hastanesi is offering early intervention programs in Turkey. Turkish Spastic Children Foundation is also offering early intervention program as an NGO.

3.5 Conclusion

In some countries there are local early intervention teams formed under the university roof, while others have more comprehensive and structured early intervention teams. The number, quality and quantity of these teams need to be increased in order for effective and scientific intervention approaches to disabled, premature and risky infants.

4 Comparative findings

4.1 Introduction

4.2 Country overview

	FLANDERS (BELGIUM)	**BULGARIA**	**ROMANIA**	**TURKEY**
1. General information				
1.2. Nº population newborn babies with disabilities and complex needs				
1.1. Nº population of premature babies with disabilities and complex needs				
1.3. nº/prevalence newborn babies with disabilities and complex needs (number of children per children born alive)				

	FLANDERS (BELGIUM)	**BULGARIA**	**ROMANIA**	**TURKEY**
2. State policy in the field of medical and social support of families with newborns with disabilities at the level of prenatal care and maternity ward				
2.1. State of the art of the medical and other staff, timing, and their roles during the prenatal, natal and post-natal follow up				
2.2. Legislation and policies for medical and social support of families of newborns with disabilities				

	FLANDERS (BELGIUM)	**BULGARIA**	**ROMANIA**	**TURKEY**
3. Care services and Psycho-social support provided to families of newborns with disabilities at maternity ward level				
3.1. Care services available for families of newborns with disabilities at maternity ward level ward level				
3.2. Psychosocial support provided to families of newborns with disabilities at maternity ward level				
3.3 NGO support of families of newborns with disabilities at maternity ward level				

	FLANDERS (BELGIUM)	**BULGARIA**	**ROMANIA**	**TURKEY**
4 Existing educational/training programmes for medical staff working on the maternity ward level dedicated related to communication and interaction with families of newborns with disabilities and complex needs				
4.1.Formal education	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse
4.2. Non-formal learning	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist

	FLANDERS (BELGIUM)	BULGARIA	ROMANIA	TURKEY
4 Existing educational/training programmes for medical staff working on the maternity ward level dedicated related to communication and interaction with families of newborns with disabilities and complex needs				
	Nurse	Nurse	Nurse	Nurse
3. Work based trainings	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse	**PER TYPE:** Doctor-gynaecologist Midwives Genetic expert Neonatologist Paediatrician Psychologist Nurse

5 Conclusion