







A – Research concept and design
 B – Collection and/or assembly of data
 C – Data analysis and interpretation
 D – Writing the article
 E – Critical revision of the article
 F – Final approval of article

Received: 2020-11-24

Accepted: 2020-12-29

Published: 2021-01-03

Monitoring the development of infants and children at risk of disability. Recommendations of the Children and Youth Rehabilitation Section of the Polish Rehabilitation Society

Jolanta Taczała*¹ , Lidia Perenc² , Małgorzata Szmurło³ ,
 Olga Wolińska⁴ , Iwona Maciąg-Tymecka⁵ , Piotr Majcher⁶ 

¹Polish Rehabilitation Society (PRS), Head of Children's and Youth Rehabilitation Section of PRS; Department of Rehabilitation, Physiotherapy and Balneotherapy, Faculty of Health Sciences, Medical University of Lublin; Neurological Paediatric Rehabilitation Ward, University Paediatric Hospital in Lublin, Poland

²Polish Rehabilitation Society (PRS), Board of the Children's and Youth Rehabilitation Section of PRS; Clinical Regional Centre of Rehabilitation and Education for Children and Youth, 2nd Regional Hospital in Rzeszów; Health Science College, Medical Science Institute, University of Rzeszów, Poland

³Polish Rehabilitation Society (PRS), Board of the Children's and Youth Rehabilitation Section of PRS; St. Louis Regional Specialized Children's Hospital in Krakow, Rehabilitation Center in Radziszow, Poland

⁴Polish Rehabilitation Society (PRS), Deputy Head of Children's and Youth Rehabilitation Section of PRS; Clinical Regional Centre of Rehabilitation and Education for Children and Youth, 2nd Regional Hospital in Rzeszów; Medical Science College, Medical Science Institute, University of Rzeszów, Poland

⁵Polish Rehabilitation Society (PRS), Board of the Children's and Youth Rehabilitation Section of PRS; The Higher School of Physiotherapy in Wrocław; Rehabilitation Center Krok Po Kroku, Gdańsk, Poland

⁶Polish Rehabilitation Society (PRS), President of PRS; National Consultant in Medical Rehabilitation; Department of Rehabilitation, Physiotherapy and Balneotherapy, Faculty of Health Sciences, Medical University of Lublin; Rehabilitation Ward, 1st Military Research Hospital with Policlinic in Lublin, Poland

*Correspondence: Jolanta Taczała; Medical University of Lublin, Poland; email: jolantataczala@umlub.pl

Dear Editor,

Infants born prematurely or those with a life or health threatening situation during the prenatal period are referred to as “risk children”. Disorders and/or delays in psychomotor development are statistically more common in them than in healthy children [1,2]. The most serious are the consequences of early brain damage, having a permanent character. Children from this group

may develop such disease syndromes as: cerebral palsy, autism spectrum disorders, intellectual disability and other developmental pathologies [3–5].

A structured perinatal care program for a “at risk” pregnant woman and highly specialized neonatological care in reference hospitals covers the period until the child is discharged from the neonatal ward. During



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a several-week hospitalization, a “at-risk” infant experiences numerous diagnostic and therapeutic medical procedures performed by “foreign hands” of medical staff. These are, of course, necessary actions that save life and health, but are not indifferent to the child and its parents [6]. After hospitalization, parents are referred to many specialist clinics, including rehabilitation. Opportunities for specialist consultations and rehabilitation services are usually located in various medical facilities, often located far from home. Few centers offer Children’s Coordinated Care (DOK), dedicated to children diagnosed with severe and irreversible disability or an incurable life-threatening disease, which arose during the prenatal stage of the child’s development or during childbirth, and to premature babies born before the 33rd week of pregnancy (Regulations of President of the National Health Fund No. 125/2016 / DSOZ).

The aim of the article is to present a model for monitoring the development of infants at risk of disability, implemented in the Rehabilitation Day Ward. It is based on modern, scientifically documented methods of diagnosing developmental disorders and complies with the concept of the International Classification of Functioning, Disability and Health (ICF) [7,8]. Detailed eligibility criteria for early rehabilitation and the principles of cooperation with parents are described. The preliminary results of a 2-year observation of extreme premature babies according to the described model are also presented.

The scheme of functional diagnosis and rehabilitation planning according to the ICF concept is shown in Figure 1.

Organization of work in the rehabilitation day ward

A specialist in medical rehabilitation, monitors the psychomotor development of infants and conducts early rehabilitation, in cooperation with other members of the rehabilitation team. The most common reasons for referring infants to the rehabilitation day ward are: disorders or delay in psychomotor development, torticollis and postural asymmetry, abnormal muscle tone, prematurity, perinatal asphyxia, birth defects of the brain and others. The doctor qualifies patients for care based on:

- an interview with parents, taking into account their concerns and the level of anxiety resulting from the past stress
- analysis of medical records, assessing risk factors for developmental disorders
- medical examination, an important part of which is the neuropsychiatric assessment, covering all spheres of psychomotor development.

Research on psychomotor development is carried out on the basis of milestones: gross motor skills, fine motor skills, communication, cognitive functions, and socio-emotional functions. The authors recommend the use of those described by CF. Dosman et al. evidence-based milestones [9]. The skills that children should achieve are organized and adjusted to specific age ranges, their lack is described as alarm symptoms, the so-called “red flags”. For premature babies, the adjusted age in the first year should be taken into account, and in extreme premature babies even in the second year of life.

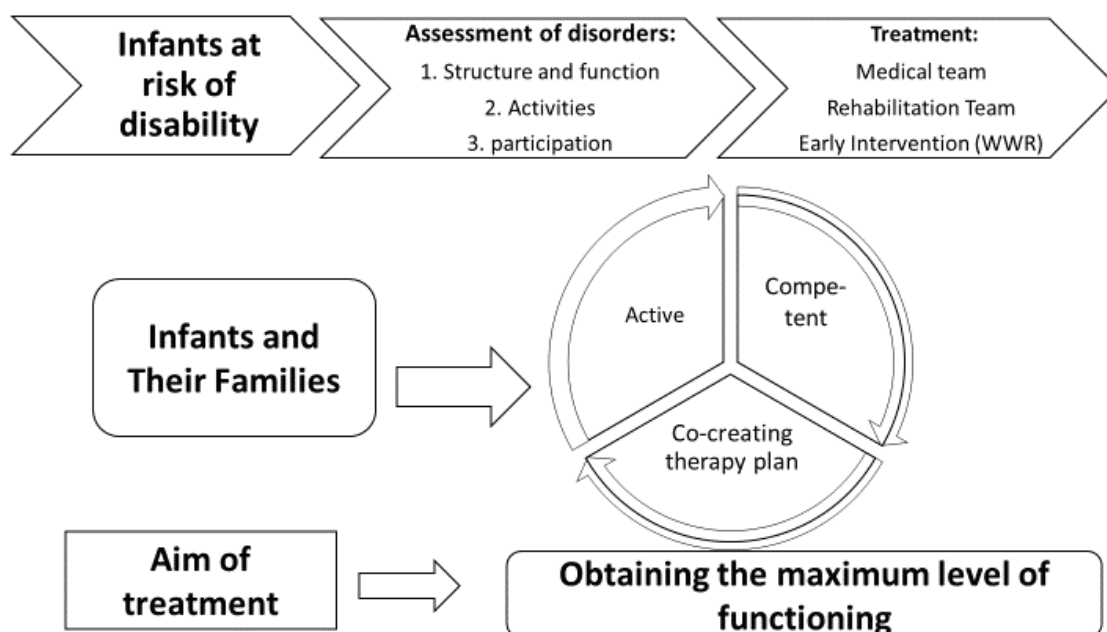


Fig. 1. Functional diagnosis and rehabilitation planning for infants at risk of disability

Tab. 1. Monitoring the development of children up to 36 months of age, medical evaluation scheme

Age of the child/ type of assessment	1 month	2 months	4 months	6 months	9 months	12 months	18 months	24 months	36 months
Posture symmetry:	SP/PP	SP/PP	SP/PP	SP/PP	SP/PP/PSIT	SIT/ST	SIT/ST	SIT/ST	SIT/ST
Movement pattern symmetry	SP/PP	SP/PP	SP/PP	SP/PP rotations	Creeping, rotations	Crawling, rising up	Walking	Walking, running	Walking, running
Trunk muscle tone – central stabilization	Correct/incorrect	Correct/incorrect	Correct/incorrect	Correct/incorrect	Correct/incorrect	Correct/incorrect	Correct/incorrect	Correct/incorrect	Correct/incorrect
Muscle tone disorders (Tardieu scale): UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL
Selectivity of movements: UL/LL	-	-	-	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL	Correct/incorrect UL/LL
Global Movement Assessment, (Prechtl method)	Correct/incorrect	Correct/incorrect	Correct/incorrect	Correct/incorrect	-	-	-	-	-
GMs	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
FMs	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
COM	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
COG	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No
SO-EM	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No	Yes/No

SP – supine position, the child lies on his back; PP – prone position – the child lies on his tummy; SIT – sitting position; ST – standing position; UL – upper limbs; LL – lower limbs; RFs – alarm symptoms, describes by CF Dosman at al.; Spheres of psychomotor development: GMs – gross motor skills; FMs – fine motor skills; COM – function of communication and speech development; COG – cognitive functions, SO-EM – socio-emotional functions.

The doctor issues a referral for rehabilitation in the event of, for example, abnormal muscle tone or movement patterns, communication and cognitive disorders, and “warning signals” in specific areas of psychomotor development. After completing the therapy, the doctor assesses the achieved effects and continues the observation. During development monitoring, clinical symptoms may indicate the need to refer to other specialists in order to make or verify the diagnosis, eg. to a neurologist in the case of cerebral palsy symptoms, epilepsy, to a psychiatrist in the case of suspected autism spectrum disorders and others [1,5].

Thanks to medical observation and cooperation with therapists, and above all parents, the doctor is able to carefully monitor psychomotor development and targeted qualifications for early rehabilitation.

Principles of medical examination and monitoring of psychomotor development

The doctor selects infants for the rehabilitation day ward according to the rules described above. The collected history and analysis of medical records allow for a preliminary assessment of the risk of developmental disorders. Neuropediatric examination includes elements of the HINE neurological assessment (the scheme is available on the website: <http://hammersmith-neuro-exam.com/contact-us/>), assessment of posture symmetry, movement pattern and muscle tone [10]. To assess motor disorders in infants in the first six months of life, it is recommended to use the global movement assessment according to Prechtl [11]. It is a method of high and documented diagnostic and prognostic value. From the age of 6 months, the study design includes the assessment of spasticity according to the Tardieu scale (recommended for use in pediatrics) and the presence of selective movements of the upper and lower limbs in spontaneous motor movement [12].

The authors recommend examination by a unified scheme described in Table 1, including the observation of children up to 3 years of age.

At each meeting, the doctor discusses the child’s developmental abilities with the parents and provides information about the next stages of development. During the controlled visits, the doctor may notice disturbing symptoms, e.g. inhibition of development, suspicion of epilepsy, genetic and metabolic diseases, autism, etc. Then he refers to other specialists to expand the diagnosis process and perform additional tests to verify the medical diagnosis – neurological, genetic, psychiatric or otherwise. On the basis of a medical examination, taking into account the alarm symptoms of developmental milestones, the doctor sets the date of the next follow-up visit or issues a referral for rehabilitation.

Criteria for early rehabilitation of premature babies

Table 2 presents the dates of medical examinations and qualification criteria for rehabilitation. It should be noted that skills described as “red flags” are not synonymous with pathology. An article by CF Dosman et al describes that 90% of the child population achieves certain skills at a certain age (90th percentile). This means that 10% remains – for individual analysis and taking into account all factors influencing the development. The authors refer to the source material of the CF Dosman article, where the alarm symptoms (red flags) of developmental milestones for children from birth to 5 years of age are described in detail [9].

Tasks of therapists involved in early rehabilitation of infants

Physiotherapist – the basis of physiotherapy for infants from the risk group is constant cooperation with the doctor and all members of the rehabilitation team involved in the child’s rehabilitation. After receiving the referral, the physiotherapist performs a physiotherapeutic assessment in accordance with the rules assigned to the profession and plans the therapy. Physiotherapeutic assessment should be based on the knowledge of proper motor development and standardized assessment methods (Prechtl, Test of Infant Motor Performance, Alberta Infant Motor Scale) [11,13]. Both the results of the diagnosis and the methods of conducting the therapy, as well as its effects, should be documented, in accordance with the competences and requirements of the physiotherapist profession.

Psychologist – cooperating in the rehabilitation team, plays an important role in the process of monitoring development, stimulating the development of cognitive and socio-emotional functions, and assessing the child’s functioning in the context of the family. The applied scales and developmental tests (Children’s Developmental Scale, etc.), screening tests for spectrum autism disorders (The Modified Checklist for Autism in Toddlers, Screening Tool for Autism in Toddlers) allow for early diagnosis of disorders and early intervention in this area [14].

Speech therapist – in the case of the assessment and rehabilitation of infants and young children, the presence of a special speech therapist dealing with communication disorders in children with brain damage in the team is necessary. The scope of his competence is to help in the event of disturbances in food intake and communication development disorders. Like a psychologist, he observes early symptoms of pervasive developmental disorders using the screening tests mentioned above.

Occupational therapist – his task is to help in achieving independence in everyday activities. For infant it

Tab. 2. Criteria for rehabilitation of premature babies for individual therapists

Age/Therapy	Physiotherapy	Psychological therapy	Speech therapy	Occupational therapy
1 month	Red Flags! Parents' care mistakes which perpetuate incorrect posture and movement patterns of the newborn; Posture asymmetry (fixed) *; Incorrect GMA	Red Flags High levels of parental stress	Red Flags Feeding disorders	Red Flags Disorders of the daily activities of the infant ***
2 months	Red Flags Parents' care mistakes which perpetuate incorrect posture and movement patterns; Posture asymmetry (fixed) *; Persistent extension pattern **; Incorrect GMA	Red Flags High levels of parental stress	Red Flags Feeding disorders, abnormal oral reflexes	Red Flags Disorders of the daily activities of the infant ***
4 months	Red Flags Persistent asymmetry of posture and movements *; Persistent extension pattern *; Low muscle tone of the trunk; High muscle tone of limbs; Incorrect GMA	Red Flags High levels of parental stress	Red Flags Feeding disorders, abnormal oral reflexes; monotonous vocalization	Red Flags Disorders of the daily activities of the infant ***
6 months	Red Flags Persistent asymmetry of posture and movements *; Persistent extension pattern **; Low muscle tone of the trunk; High muscle tone of limbs	Red Flags Lack of smile to the caregiver, no distinction between friends and strangers	Red Flags Open mouth, poor saliva control, monotonous vocalization	Red Flags Disorders of the daily activities of the infant ***
9 months	Red Flags Asymmetry of the sitting posture; Low muscle tone of the trunk; High muscle tone of limbs Lack of selectivity UL/LL	Red Flags Concentration on objects and not on people, lack of interest in the environment, problem with stabilizing the phase of the day and night	Red Flags not making sounds to get attention	Red Flags Disorders of the daily activities of the infant ***
12 months	Red Flags Asymmetry of the sitting/standing posture; Low muscle tone of the trunk; High muscle tone of limbs; Lack of selectivity UL/LL	Red Flags Lack of seeking comfort from the caregiver in the event of illness, fatigue or pain	Red Flags No reaction to the name	Red Flags Disorders of the daily activities of the infant ***
18 months	Red Flags Asymmetry of sitting/standing/posture and during walking; Low muscle tone of the trunk; High muscle tone of limbs; Lack of selectivity UL/LL	Red Flags no common field of attention, the child focus on objects rather than people	Red Flags not able to speak some words	Red Flags Disorders of everyday activities, inability to play together
24 months	Red Flags Asymmetry of sitting/standing/posture and during walking; Low muscle tone of the trunk; High muscle tone of limbs; Lack of selectivity UL/L	Red Flags no symbolically represented games and role-playing, no common field of attention	Red Flags not able to speak many words	Red Flags Disorders of everyday activities, lack of ability to play in dependently and together
36 months	Red Flags Asymmetry of sitting/standing/posture and during walking; Low muscle tone of the trunk; High muscle tone of limbs; Lack of selectivity UL/L	Red Flags no games with symbolic pretending, no contact with peers, behavioral disturbances in social contacts	Red Flags lack of ability to build 3–4 word sentences, speech incomprehensible by the environment	Red Flags Disorders of everyday activities, inability to use cutlery or crayons efficiently

1 "Red Flags" alarm symptoms of evidence-based milestones by Dosman et al, in all spheres: GMs, FMs, COM, COG, SO-EM [9]; *posture asymmetry (fixed) – the child cannot be placed in the symmetry position; ** extension pattern – no spontaneous physiological flexion pattern (UL and LL are raised); instead the baby tries to straighten up in all positions; *** – disorders of the infant's daily activities – if there are no occupational therapists in the center, the therapy is carried out by other therapists.

includes sleeping, eating, getting to know the family, in older children – getting dressed, eating, playing. In some countries, for an occupational therapy the care is already organized in neonatal intensive care units. Their activity is directed primarily to parents who should be prepared to care for their children after discharge from hospital [15].

Disturbances in sensory processes (SI) in children – premature babies are particularly vulnerable to them. The shorter the duration of pregnancy, the more immature the sensory organs are, so the way of perceiving, exploring the environment and analyzing sensory stimuli coming from the outside world is more disturbed. The SI therapist is not always present in the rehabilitation team. Both the medical rehabilitation specialist and all therapists who monitor the development of infants and early rehabilitation should take into account sensory processing disorders in their diagnostic and therapeutic procedures [16].

Principles of cooperation with parents

When monitoring the development of premature babies, it is very important to recognize the important role of parents from the very beginning. According to the ICF concept, the therapeutic team should be the focus on the child and the family [7,17]. Staff overly focused on the child, without taking into account the parents' needs, can lead them to feel excluded, resulting in inappropriate care. Parents fear that they care for their child badly. Professionals should support parents as much as possible so that they themselves can help their children [18]. The earliest contact of therapists with parents is possible in neonatal intensive care units. Already there, a lot of information on the principles of proper care to stimulate children's development can be provided. The possibility of support and assistance in the observation of development after hospitalization should also be presented. Such an offer is the described model of care for premature babies, implemented in the day rehabilitation ward. It is an ordered, interdisciplinary model of monitoring psychomotor development up to the age of 3.

Summary

Progress in the field of neonatology enables the survival of children born in a life and health threatening condition [19,20]. The next goal of medical activities is to aim for the lowest possible percentage of developmental disorders in children from the "risk group". The measure of success, described in scientific studies, is the survival of children with no significant developmental deficits at the age of 2 [4,21]. The early initiation of rehabilitation of infants allows to use the

enormous potential of the maturing brain and its plasticity [22–24]. It should be remembered that referral for rehabilitation must be a very balanced decision. The intervention is not indifferent to the child and his family [25,26]. The doctor is responsible for the diagnosis of psychomotor development disorders and the qualification for rehabilitation of infants from the "risk group". The most competent specialist in this case is the medical rehabilitation doctor. This is due to the program of specialization and professional competences as well as direct cooperation with members of the rehabilitation team. The rules of qualification for rehabilitation should include the medical examination with analysis of risk factors for developmental disorders based on medical documentation. The authors also recommend taking into account the "red flags" of evidence-based milestones [9,10,27,28].

The described development monitoring model has been used practically since 2014. The published preliminary results of studies on monitoring the development of premature infants show the usefulness of this scheme of management. A high prognostic value of the "red flags" of psychomotor development of the examined children in the 9th month of the corrected age was observed, in relation to the 24th month of the actual age [29]. Development monitoring also allowed for the identification of almost half of extremely premature babies who did not require rehabilitation during the first 2 years of life. More than 2/3 of the entire group of extremely premature infants at the age of 2 achieved the developmental norm in all areas [30], which in relation to the studies of other authors is a very good result [21,31]. The presented scheme of interdisciplinary care for infants at risk of disability is recommended by the Board of the Children and Youth Rehabilitation Section of the Polish Rehabilitation Society. It is in line with the ICF concept, where the child and his family are the focus of the treatment team. The team of specialists strives to achieve the maximum level of functioning in everyday life and participation in social life.

Funding

This research received no external funding.

Conflicts of interest

The authors declare no conflict of interest.

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