

Aiding the Family of a Child with Disability in the Process of Early Intervention – Diagnostic-Rehabilitation Model

The presented, in the present study, proposition of the model diagnostic-therapeutic conduct project for children endangered with disability and their families is a chance of inscribing itself in the national actions in favor of the improvement of services in the early intervention. The proposed project takes into account the current tendencies in the domain of theory and practice of early intervention, presented and recommended in the “Early intervention in Europe”, elaborated by the European Agency of Education Development of Pupils with Special Needs. The report determines the summary of the “Early intervention in Europe” project, realized in the years 2003-2004 by experts from 19 European countries. The aim of the project was the analysis of the state of actions from the domain of early intervention, defining the most important problems in this area, as well as formulating guidance and recommendations, serving the improvement of service quality for the children endangered with disability and disabled, as well as their families.

Intervention in early childhood: outline of the conception in the EU countries

The European and international documents published in the last 20-30 years, consisting conceptions, principles and methods of intervention in Early childhood (Early Childhood Intervention – ECI) show the evolution of ideas and theories. Numerous works of authors, presenting different theoretical approaches, contributed to the changes of conceptions and – in consequence – practice:

1. They developed a new ECI conception, in the direction of the interdisciplinary of the approach, with regard to such fields as: health, education, social science, and, in particular, psychology. This corresponded with the new situation, because, in the past, these sectors had a comparatively different and not always coherent range of influences.
2. They underlined the change of the direction of intervention, focused hitherto mainly on the child, in favor of a wider approach, in which the emphasis is directed on the entire family and the local environment (Peterander and others, 1999; Blackman, 2003).

Numerous theories in psychology and education, beginning from theories focused on the nature that are set against the dichotomy of upbringing, perceiving the child’s development as an open process (*tabula rasa*), to Gisell’s developmental theory (1943), Skinner’s theory of operant conditioning (1968) and Piaget’s genetic epistemology, had an influence on the consolidation of a wide approach to ECI. The further development of theory was presented by other authors, who put special emphasis on the meaning of the following matters:

- a) The role of the family and the guardians in the child’s development – bond theory (Bowlby, 1980; Aisworth et al., 1978);
- b) The influence of social interactions – social learning theory (Bandura, 1977), social development theory (Vygotsky, 1978), transactional model of communication (Sameroff and Chandler, 1975; Sameroff and Fiese, 2000);
- c) The influence of interactions with others and the environment on the development – ecological theory of the man’s development (Bronfenbrenner, 1979).

The report presents the evolution in the field of early intervention, the passage from the model of intervention that is focused on the child, to the ecologic-system model, in which actions are also directed at the family.

This new theoretical perspective allows to define the child's development in four aspects (Porter, 2002): holistic, dynamic, transactional, and individual. Realizing the ecological-system approach **as a model of reference for ECI**, assures a systematic way of analyzing, understanding, and registering that, what happens with children and young people in their families in a wider context of their lives (Horwath, 2000).

In the ecological-system concept, the authors of the report use several chosen definitions in order to present various aspects of the approach in early intervention (ECI):

Guralnick (2001) defines ECI as a system designed to support the family patterns of interaction, which best promote the child's development. According to this author, the most essential is the parent-child arrangement, the child's experiences initiated by the parents and help, which the parents can receive, in order to maximize care over the child's health and its safety.

Shonkoff & Meisels (2000) assume that ECI consists of services in various fields of life, provided for the child from birth to the age of five. The main aims are: promoting health and well-being of the child, strengthening the occurring competences, minimizing developmental delays, removing the existing and occurring disabilities, preventing functional damages, promoting parent adaptation.

Blackman (2003,p.2) thinks that the "aim of intervention in early childhood is preventing and minimizing physical, cognitive, emotional limitations in small children with biological and environmental risk factors". This author underlines the key role of the family as a factor of success of intervention actions.

Dunst (1985,p.179) defines ECI as "the protection of the support (and resources) for families with small children by the members of informal and formal networks (institutions) of social support, who directly and indirectly have influence on the functioning of the family and child".

The conducted theoretical analyses, as well as the existing range of practical experiences, made possible for the experts of the Agency to propose the European definition of the ECI:

ECI is a gathering of services for very small children and their families, assured on their request, in a suitable (in a defined period of the child's life) time of the child's life, through:

- *Assuring and strengthening the child's development*
- *Strengthening one's own family competences*
- *Promoting the inclusion of the family and child to the society.*

The actions have to be held in the child's natural surrounding, at best on the local level, oriented at the family, with the co-operation of the interdisciplinary team of specialists.

Taking into consideration all of the characteristics and principles determining the bases of the ECI conception, we notice two crucial elements that give the specific character to the work in this field. They are: the child's *early age* and the *complex character of influences*.

The connection of these two factors requires:

- Unification of the efforts of various experts
- Interaction between the intervention participants
- Coordination of all engaged services
- Direct inclusion and participation of the parents (and other family members).

Only an effective connection of distinguished actions can assure good results of every intervention directed at small children. This notion clearly directs attention on the **influence**,

that ECI has. Some authors treat ECI as a way of assuring effective means to fight with further social and/or educational exclusion (Nicaise, 2000).

Guralnick (1997) arguments that the study conducted in 1970 “*demonstrated a general efficiency and feasibility of intervention programs in early childhood in children born with risk, as well as those with settled disabilities*”. Further research, in the opinion of the author, have to define “*which interventions are the best, for whom, in what conditions, and with what final effect*”.

Discussions, conducted during working meetings on the ECI project, have revealed that in order to measure influence – ECI efficiency – all participants, that are engaged in the intervention, have to be considered:

- **the child:** progress and self-perceiving of oneself by the child
- **family:** level of satisfaction
- **experts:** the level of satisfaction and competences
- **society (community):** level of satisfaction (from executed tasks), benefits, costs/effects of investment

Also elements, having a crucial meaning for the realization of a new ECI conception, resulted from the report: accessibility, proximity, financial accessibility, variety of services.

In order to effectively realize the above mentioned model, fulfilling several conditions is indispensable:

- 1) Exact cooperation between the Health, education, and social care services, which together are responsible for the organization and financing of ECI
- 2) Work in interdisciplinary teams
- 3) Elaboration of the Individual Program of Family Help, which includes the needs of the child and family, strong sides, priorities, settled goals, and actions that ought to be taken, as well as the evaluation of their execution.

Proposal of an algorithm of diagnostic-rehabilitation conduct for children endangered with disability or disabled resulting from an early brain damage and their families – proposal of standards of an integrated system of early intervention

Taking into consideration the theoretical contexts, research output and recommendation contained in the report, one should recognize, that early intervention, as a system of complex services, does not exist in the Polish system of care over the child and his family. Despite the recommended ecological-system approach as a reference to the ECI actions, in different European countries, in his also Poland, there occurs a dichotomy between a medical and social approach to the problem of intervention in small children.

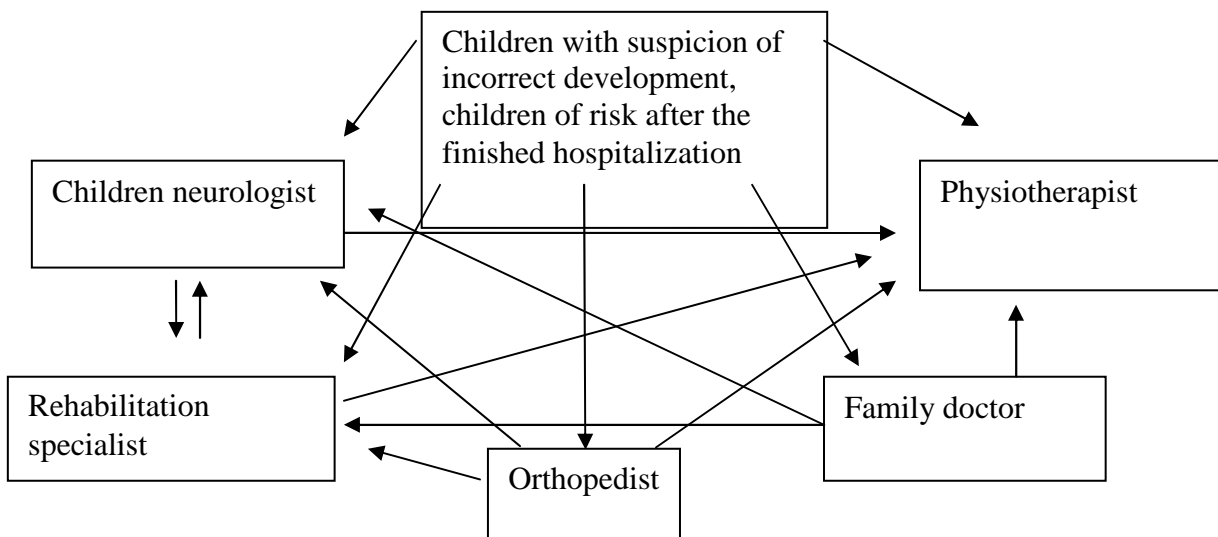
The constructive evaluation of the situation and the hitherto forms of help caused the undertaking of innovatory actions, having on aim the settlement of the chaos reigning in the area of early intervention. The test of the ecosystem approach, that includes European achievements and also national experiences, is the proposition of the algorithm of diagnostic-rehabilitation conduct, elaborated by the Board of the Children and Youth Section of the Polish Rehabilitation Institution. The proposal of diagnostic-rehabilitation conduct towards the child and family bases on the well-ordered system of reliable diagnosis, multi-profile and multi-specialist care for many years – till the adult age, to the achievement of maximum efficiency and independence of a disabled person, so called, “Project for life”. In the model, a leading doctor is proposed to the parents – he is responsible for the diagnosis and therapy “from the beginning to the end”, for the cooperation with other specialists and the coordination of the treatment process. All integrated actions in the range of support are

undertaken considering the proposed standards, conditioning the achievement of possibly the highest level of functions of the disabled people in the range of:

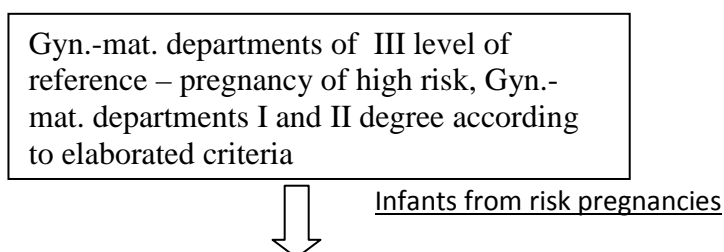
- accessibility of support
- complex and multi-profile support
- continuity and planning of support
- effectiveness and safety of support
- support that respects the subjectivity and dignity of the patient/pupil and family

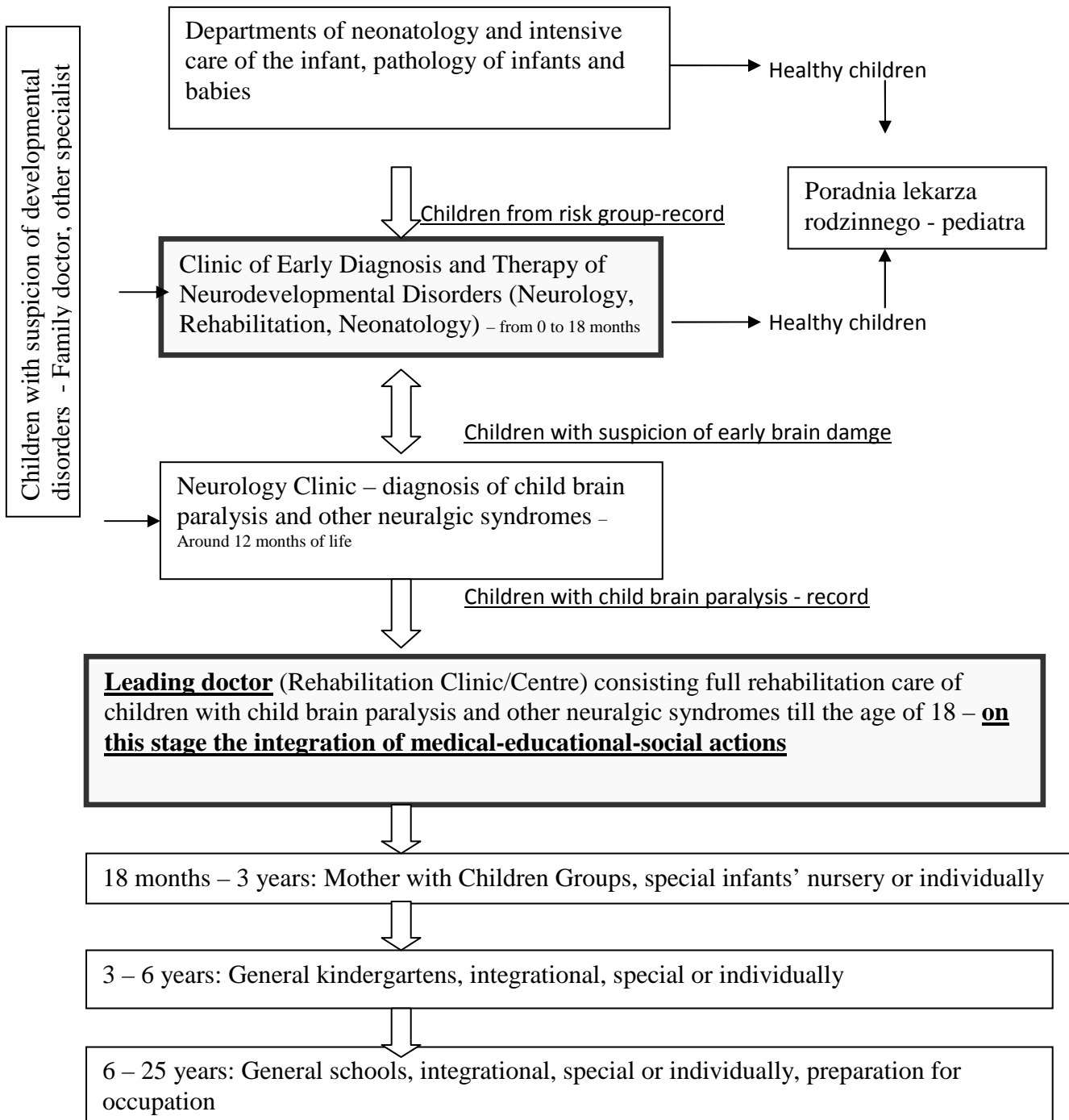
The schema of conduct for children endangered with disability resulting from early brain damage – **current state**

Early diagnosis of developmental dysfunctions and early rehabilitation



Proposition of an algorithm of diagnostic-rehabilitation conduct for children endangered with disability resulting from early brain damage





The decision about rehabilitation is made together by:
Parents– Leading doctor – Psychological-Pedagogical Counseling Centre

Justification

The undertaken subject, as an effect of current reflections of the environment of experts and parents on the condition of the offer of services in the Polish system of between-department help for the child and family, sails out due to several causes. First of all, the

existing output of clinical experiences from the recent years, as well as the access to modern research techniques (neuro-diagnosis), allows for a more effective diagnostic-rehabilitation conduct towards the child and his family. Secondly, perceiving disabled people as rightful citizens, with accruing law to use all spheres of social life, contributes to the improvement of their quality life, and at the same time, acknowledging their autonomy.

Zakończenie

The proposed model of the diagnostic-rehabilitation procedure, based on the perspective of the ecosystem embrace of the situation of the child with developmental problems, fully gives the modern and dynamic approach in early intervention.

Taking into consideration the existing tendencies it is possible to certify that the proposed model of actions, considered as multi-field services (educational and therapeutic), offered to the children in aim of improving their health state, in connection with a support plan for their families, requires acknowledging it as a general duty of the families, experts, and politicians on the national and local level.

At present, the Board of the Main Polish Rehabilitation Institution appointed an evaluation committee, which has the task of preparing a project for the recommendation to the proper opinion forming environments.

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