

RESILIENCE IN CHILDREN AND ITS IMPORTANCE FOR EARLY INTERVENTION

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Abstract: *The paper focuses on questions of early support and early intervention in children with developmental disabilities and their families. The term “resilience” is explained in the context of early support. Resilience occurs when unfavourable and specific conditions of a child co-occur and interact with the environment. We focus on the possibilities offered by the great plasticity of CNS in the early age. We define early intervention in accordance with the Act on Social Services. In conclusion the paper presents a research analysing the experience of mothers of children with severe disabilities receiving external support at early and pre-school age.*

Key words: *resilience in children, early age, health disability, plasticity of CNS, early intervention*

Theoretical Points of Reference

Resilience develops from the conflict between adverse and life-specific conditions and protective factors which the child can obtain in interaction with the environment (see Figure 1). Resilience relates to the “dynamic, transactional process between child and environment” (Wustmann, C. 2005, 193 in Leyendecker, Ch. 2010, p. 40), which is the following:

- relational size (related to difficult life circumstances and protection factors)
- relative size, ie. there is no absolute limitation (Gabriel, Th. 2005, 207 in Leyendecker, Ch. 2010, p. 40)

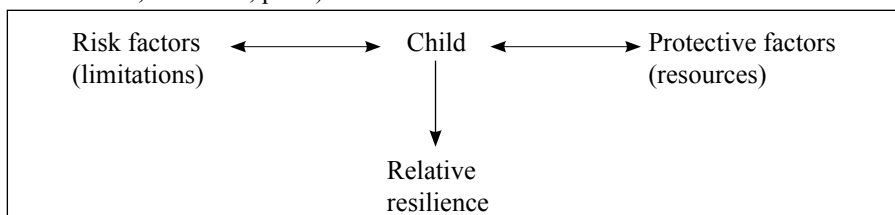


Figure 1: Character of the resilience process in the constellation of limitations and resources

It is important to accept a the general view that each child derives individual resilience from its own personality rather than from the supportive interaction with the environment. Also, the term of resilience ability can be derived from the child's individual ability. Therefore it would be more accurate to speak about resilience situation or constellation.

Protective factors (resilience factors)

Personal resources (the child)

- Positive temperament characteristics that elicit attention, affection, and social support from the carers (open, communicative, active child)
- Feeling of safety and ensuing joy of exploration
- Ability to solve problems
- Acquisition of own experience and beliefs
- Positive self-concept, high degree of self-perception
- Experience of responsibility
- Active behaviour with the aim to achieve something (e.g. mobilise social support)

Social resources (inside and outside the family)

- A stable emotional relationship with one of the reliable carers in the family supporting confidence and autonomy
- Emotionally positive, supportive and structured education climate
- Family cohesion (despite the substantial burden of the birth of a child with severe disability)
- Models of positive coping with the situation
- Competent and caring adults outside the narrow circle of family who support the trust and family ties (grandparents and other relatives, neighbours, acquaintances, early care workers, educators and teachers)
- Positive experience with kindergarten and school

These personal and social protective factors cannot be viewed as constant or independent of each other, but rather as factors that are in dynamic relation to each other and have, similarly to risk factors, the nature of probability. In this context resilience is the opposite of the negative development probability. We can say that the more risk factors there are in a child and the more vulnerable the child is (the more limitations there are), the more needed are the protective factors, ie. protective resources. The importance of social resources in the research of resilience shows that educational theory and resilience are in harmony (Leyendecker, Ch. 2010).

Resilience must be supported at three levels:

1. in the child
2. in the child's immediate environment (family)
3. in the child's broader social environment (neighbours, nursery, kindergarten, school, neighbourhood)

It means that the supportive approach concentrating on one level only cannot be efficient and, as a consequence, cannot succeed.

Children with risky development in early support

Children that need early support can be divided into two groups:

- *Children with biological risks*, with disabilities, are more vulnerable and need a much more intense, longer and competent supportive, protective and accompanying interaction with adults as compared with intact children.
- *Children with psycho-social risks* (poverty, neglect, mentally ill parents, etc.), where the poverty is a risk factor especially if it is expressed in a prominent way and interferes with the child care and education. In such cases our intervention, contacts and cooperation with the family are substantially limited.

The concept of resilience in early age child development is that we educate a child with developmental disabilities with reasonable optimism that would prevent an excessively pessimistic assessment of the child's life prospects. Resilience, as opposed to the probability of the child's negative development, is an incentive and a chance to see resources for improvement even in the child's difficult situation. It is crucial to be able to take advantage of these resources and support them.

Central nervous system plasticity

The plasticity of the central nervous system (CNS) has important implications for therapeutic and educational measures in the prevention of developing disorders or disabilities. The term of plasticity raises a number of associations: in relation to the brain, for example, we think of the possibility of shaping and changing this organ, modifying or adapting its functions in favour of certain needs. The brain controls our behaviour through different functional systems. Their function is monitored even before birth, by ultrasound for example. After the birth they are further analysed using polygraphic examinations and mother-child interaction observation. The differentiated accord of genetic factors and environmental influences that act as epigenetic components are essential prerequisites for all developmental processes.

The plasticity is an essential characteristic of the nervous system. However, it is dependent on certain conditions and has its limits. The plasticity is important for compensating functions of the central nervous system after injury or damage. The knowledge of plasticity should help us in planning and implementing some educational and therapeutic measures. Therapy and support should take into account the specific needs of each child, as well as its environment (Korsten, S., Wansing, G. 2000).

Having a good picture of each child with respect to its **strengths and weaknesses** in order to properly understand the development of their personality and the possibility of interaction is the basic prerequisite for effective special educational support (Vitková, M. 2006). Therapy and support have to take into account the specific needs of each child but overloading and excessive influence of stimulation must be avoided and the child's environment must be involved. This is why a certain level of plasticity is also required

from therapists and teachers. Only then the possibilities of changes defined at various levels can be fully exhausted not only in the field of forming neuronal connections or function systems but also in the field of the handicapped child's social integration.

Early care

Very young children with severe disabilities usually stay in their families. In this case the family is a kind of institution and its framework of care is considered to be particularly suitable and qualified in terms of promoting the child's development. Many articles and professional publications have been written about the integration of a severely disabled child in the family life. For example, the "continuous parenting" appears to be a problem, as a child with severe disabilities will never become an adult as regards socialisation and younger siblings will develop faster. There are many positive examples in the literature from which it follows that the family learns to cope very well with the difficult situation, it acquires expertise, selects supportive and therapeutic offers, applies them and promotes its rights (cf. Matějček, Z. 1986, Langmeier, J., Krejčířová, D. 1998, Vagner, M. 1991). Care and education in the family is complemented by special offers inside the family as well as outside.

The Social Services Act (No. 108/2006 Coll.) establishes the institute of early care. Early care is a field of outpatient service and is provided to the child and the parents of a child with disabilities or whose development is at risk due to an adverse social situation, at the age from birth to 7 years. Social service is aimed at supporting families and promoting the development of a child with respect to its specific needs. On the basis of the Education Act (No. 561/2004 Coll.) and the related Decree (No. 72/2005 Coll. on consultancy services) educational and psychological counselling services are provided to parents of children with disabilities. These services are provided in special education centres (cf. Vítková, M. 2006, Hanák, P. 2005). Preschool children with disabilities can attend regular kindergartens, special kindergarten classes, special kindergartens, special primary school preparatory courses or various types of day care centres, particularly those providing physiotherapy. It should be noted that even if the support to families with children with severe disabilities is well coordinated and there is a good atmosphere in the family, a child with severe disabilities and its family are on a constant move between home, school and therapeutic and medical institutions.

As well as the trouble-free pregnancy, the child birth and subsequent post-partum care are crucial for the positive development of the child. The course of the delivery influences the child's further development and an acute or chronic hypoxia (oxygen deficiency) are among the major risk factors during delivery and so is an infection of the fetus and newborn baby. In many newborn babies these complications after birth can be a serious threat to the health and can significantly reduce the quality of the child's further development. Among the risks are cerebral palsy, central and peripheral eye sight disorders, hearing disorders, etc. In connection with the antenatal, intrapartum and post-partum care a questionnaire survey was conducted in Czech maternity hospitals in 2000 to 2003. The study was implemented by Aperio – Healthy Parenting Association, a civic association, the actual survey was performed by the STEM agency in 114 maternity hospitals. The survey aimed to determine what approaches, tools and services our maternity

hospitals offer, how pregnant women and mothers assess the obstetric care and what is the approach of health care professionals and mothers to alternative child birth methods. In parallel with this survey there was a public inquiry conducted by Aperio on the topic “How it is to give birth in Czech maternity hospitals”. Early diagnosis irregularities in the development of newborn children during the first three months of their lives and early intervention are essential prerequisites for a successful compensation and prevention of the serious consequences of risky births. An important question is how parents are informed about the health condition of the child in the maternity hospital and about the possible subsequent development of the child. Informing parents about severe disability of their child is always traumatising. The attending physician or paediatrician should be the persons who deliver this information to parents. The information should be complete, true and easy to understand for the parents so that they be able to decide on the future of their child on its basis.

Example: Early care – interviewing mothers of severely handicapped children

Gabriela Feistová (2009) in her doctoral thesis written under the guidance of Professor Marie Vítková focused on establishing the opinions, views and experience of mothers with severely disabled children in the period from early and preschool age to school age where the obligatory inclusion of the child in the school community is often decisive for the change in the family’s lifestyle because most of the times this means the first step toward the child’s “independence”.

For the research project the thesis author used results of the questionnaire survey in order to compare the identified information, namely information concerning the professional assistance provided to mothers after their return from the maternity hospital.

The aim of the research was to determine how the mothers perceive the daily care of their severely disabled children, to identify the mothers’ experience with educating severely disabled children, to identify their views on their children’s education, to explore how they perceive the support from experts and organisations working with children with severe disabilities. In order to obtain the most complete data the author used the technique of documentation analysis, observation, and interviews with 14 respondents. Mothers who look after children with severe disabilities at various ages were preferred. While working on the research project the author used the technique of non-standardized in-depth interviews. Before visiting families she set observation targets: observe the atmosphere in the family environment, including arrangements for disabled access, daily family routines and the attitude of the mothers and other family members to the disabled children.

The research showed that mothers still perceive an insufficient psychological support during the period after the child birth. In their responses they most frequently mentioned the lack of information at the earliest stage. Respondents confirmed their dissatisfaction with the lack of continuity among individual institutions (maternity hospital, paediatrician’s office, specialists’s office, professional pedagogical centres, primary schools), which is usually manifested in lengthy procedures concerning the child’s health.

It was interesting to find out that it is of little importance for the mothers whether their children go to school but they find it much more important to fill the child's daily programme. They perceive school as the place where their children can stay during the morning but they do not see it as the "starting line" for the children's independent life in the future. They often seek such facilities where it is possible to link educational and social services. In case of children with severe disabilities this does not yet mean health institutions (such as physiotherapy). The mothers believe it is important to find an institution that will provide comprehensive services to their children over a long period of time. The mothers relate that they do have the possibility to use various services but in their daily routines it is difficult to include them and use them on a regular basis. They also mention that their price is limiting for them. The need of supportive services preventing the social isolation of the families caring for children with severe disabilities appears to be of key importance. Marriage support should not be forgotten, as it is necessary to make sure that the family works well to provide the necessary background for all members. It is evident from the mothers' responses that it is extremely difficult to harmonise the educational, social and health care services which are all equally important for the development of children with severe disabilities. In the respondents' opinion the most important is the continuous care for the child during the day. School, in the mothers' view, is only one of the elements in this comprehensive care.

It follows from the survey that the system of education for children with severe disabilities in the Czech Republic is defined and supported with legislation but in practice the necessary conditions are not always present. It is clear from the mothers' responses that they are not sufficiently informed about the mandatory schooling of children with severe disabilities. They often said that they did not consider mandatory schooling as necessary for their disabled children. The survey points out to the need of a better coordination of services provided by individual institutions (social, educational and health care) and state administration bodies (ministries) as well as a better public awareness.

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RESILIENCE V DĚTSKÉM VĚKU A JEJÍ VÝZNAM PRO RANOU PODPORU

Abstrakt: V kapitole se zabýváme otázkami rané podpory a rané péče, věnované dítěti s vývojovým postižením a jeho rodině. Ve vztahu k rané podpoře je vysvětlen pojem resilience, která vzniká ze setkání nepříznivých a životně specifických podmínek u dítěte v konfrontaci s prostředím. Pozornost je věnována možnostem ve využití plasticity centrální nervové soustavy v raném věku ve prospěch dítěte. Charakterizovaná je raná péče dle zákona o sociálních službách. Závěrem kapitoly je uvedeno výzkumné šetření, které se týká analýzy zkušeností matek s dítětem s těžkým postižením s vnější podporou v raném a předškolním věku.

Klíčová slova: resilience, dítě, raný věk, zdravotní postižení, raná podpora, plasticita CNS, raná péče