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## Review article

## Disabled children and their family surroundings



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## ABSTRACT

The relationship between the society and disabled people has experienced various stages from mockery and condemnation to the present endeavour to create conditions for integration of persons with different handicaps into the normal life of the society. With disabled children, a significant role in this process is represented by the family which experiences various periods of dealing with the disabilities of its member from the moment when it has met the unfavourable prognosis of being handicapped and they must cope with this situation in a different way and for an extended period of time. The family will often face internal problems, as well as adversity involving their surroundings. The attending paediatrician must provide care in these cases, not only for the disabled child, but they must also influence the atmosphere within the entire family in a positive way.

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## Introduction

The health and social maturity of countries (and also the maturity of political systems) has been judged among others according to what extent they are able to care for their citizens (disabled children, seniors, etc.) within their budgets (service, benefits, etc.), as well as within the social sphere (empathy, support expression, etc.), as these citizens are in a difficult social situation and cannot live without this help. Disabled children and their parents do not often have a bed of roses. A family is an environment which is both alpha and omega regarding positive development and later it is possible for the family to integrate a disabled child into

the society. Demands on the family are very high in these cases and not every family can, is able to or wants to meet these specific demands. A paediatrician performs an irreplaceable role regarding the formation of a positive atmosphere within the family of a disabled child because they often perform not only the role of a physician, but also the role of a family counsellor and a confidant. They prepare the family with their professional attitude towards disabled children and their “intimate” environment whereas this attitude should include not only purely medical matters, but also educational, ethical and other aspects for acceptance future; bio-psycho-socio-spiritual needs of disabled individuals and to their possible integration into the society of healthy peers.

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## Terminology

The terminology has changed with the historical development of the relationship to a disability and the status of disabled people in the society. The former expressions regarding a handicapped person or a handicapped child have receded into the background recently and they are first and foremost considered a human being, a person, a man, a child and characteristics of their disability are considered secondarily resulting in expressions like: a child with a physical, mental, sensual, speech or combined disablement (handicap) [1].

“According to the professional aspect a disability can be expressed by various terms. Previously a disability was perceived more likely as a category, a defect was diagnosed and a measure followed according to the kind and stage of the disability. Contemporary conception of care and especially in terms of pedagogical means of rehabilitation much better conform perception of a disability as a dimension so a certain proportion of life” [2, p. 36]. In terms of the integration of a disabled individual in the society, additional terms like inclusion (balance of opportunities of disabled persons e.g. educational or working) [2], eventually adaptation (represents lower level of socialization than integration, it is concerned with the ability of disabled individuals to adapt themselves to the society), utility (social usability of an individual that cannot be fully socialized and is unable to live independently) and inferiority (the lowest degree of social integration which is characterised by exclusion of an individual from the society) [3].

The international classification of functional abilities presents a significant document from the World Health Organization (WHO) which is concerned with the assessment of disabled people. Originally, this document was called the International Classification of Disorders, Disabilities and Handicaps and was focused on a disabled individual considering his restriction to exercise various activities in connection with his disorder [4]. Disability is a term which expresses the impossibility to exercise certain activities [2].

*“In 2001 that document was modified. Its title was changed to International Classification of Functional Abilities. This latest conception leaves completely the term a handicap which is perceived as a misleading one and the term a restricted participation which is the cause of not being able to exercise certain activities is used instead. Participation is then perceived as a decrease of an activity which is for the individual restrictive just in the activity which is for him important in relation to social environment. The international classification of functional abilities then does not assess a man in itself but in terms of situation in which he occurs, which can be restrictive but otherwise is he healthy”* [2, p. 37].

Presently, this forms part of the care for individuals with disabilities and includes: health rehabilitation, psychological rehabilitation, pedagogical rehabilitation, working rehabilitation, free time rehabilitation and social rehabilitation. Rehabilitation, in this conception, is not to be understood only as a medical activity, but also as an interdisciplinary activity [5].

## Family with a disabled child

The integration of disabled persons into the society and their acceptance by the society, has never been a simple process.

The relatives of such individuals consider the disabled person as an outsider and they are considered to be a nuisance. They may also be ashamed of the person and condemn them.

*“The attitude towards the disabled or diminished person has been also affected – out of doubt – by pressure of external circumstance – in principle by economic situation of the group. A society which only with troubles provides its material survival (first of all enough food) or whose external life conditions are extremely hard can be only hardly assumed to allow to support an individual which cannot bring any profit to the group, more likely this individual will task the group by necessary care of him. The quality of each of group member is measured by his possible contribution for the group”* [6, p. 9].

The systematic manifestations of interest in the improvement of conditions for all of the ill and handicapped, already had been mentioned in the Middle Ages. However, they are always bound to the specific degree of social development of each society, pragmatically resulting from its requirements and needs. In addition to execration (often even abuse) of disabled persons, we often meet sophisticated care of their needs and attempts to integrate such individuals in the society. At first, institutions established by the church and later by philanthropic individuals and even secular feudalists and enlightened monarchs helped with the care of the disabled.

A family is the child's primary and most important environment and in which children are confronted with the attitudes of their parents which resulted from their previous adventures and experiences in childhood regarding their relationship to their parents, siblings and grandparents, and eventually to other relatives. In addition, there are other experiences involving relationships out of the family such as marriage. From this aspect attitude of the parents to the child is individual and every child brought into the world has an individual and unrepeatable living conditions and passes through specific developmental stages [7].

A disabled child is generally born and raised in a family therefore we often speak about the family of a disabled child. The concept of the term a family is a subject of frequent discussions among experts. Namely, it does not have to be a social group formed by blood relatives, though in this way it is legally limited in many states. Many people consider a family to be just blood relatives, thus only parents and children. Others consider a family also to include; grandparents, uncles, aunts, etc. and consider a family also to be a single parent or a couple without children. In addition, another question is whether a family is always formed only by matrimony or also through a partnership and yet another topic is a partnership of the same gender. Generally a family is presented as a social group which is “... bound by marriage or blood relationships, responsibility and mutual help” [8, p. 230]. It is formed by extended relatives and is functional, which means that it is able to solve problems which it encounters and blood bonds mutual positions, observance of traditions, etc. are typical for this type of relationship. An expected presumption of a family is solemnization of marriage and the upbringing of children. Some authors go much further and differentiate between the terms a family and home life. A family, according to them, is

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