

Health and social problems of a child with locomotor system dysfunction

Introduction

Disability in its essence is a phenomenon which has both components of medical and social nature. Caused by diseases, injuries and various types of dysfunctions it has tangible functional and social consequences. This complexity of the phenomenon of disability causes that it is described and measured on the basis of medical variables (etiology, localisation, scope of damage), on the basis of possibility of everyday functioning (self-service, locomotive faculty etc.) and on the basis of ability to perform basic social roles, adequate to a lifestyle of a given person, including ability to work¹.

Notion of **disability** includes various functional limitations of individuals in every society, caused by impairment of capability to perform certain activity in a way considered normal, typical for a human life. Such limitations may have either permanent or temporary, complete or partial character, they can refer to a sensory, physical and psychical sphere. According to Kowalik, human disability, caused by bodily injury or chronic disease, may cause organism disfunctionality, psychical disability and weaker, smaller social efficiency. It can also facilitate creation of problematic situations which, in turn, means lack of accordance between man's possibilities and demands made by the environment².

Particular problems of a child with an injured locomotor system are the results of their physical separateness which includes appearance and motor function. Separateness has a negative character, i.e. consists in lack of deformation of the limbs, alternatively changes in the spinal part and is connected with a decrease of fitness. These two aspects of physical disability are most often interlinked, i.e. that the more extensive, the more visible is disability, the larger is fitness impediment. It is also important that injuries to a locomotor system are often connected with a feeling of pain which is a consequence of the injury itself or a recovery treatment³.

Deformations and dysfunctions in a locomotor system in case of children are caused by various reasons. The most frequent are congenital defects and developmental disorders. The other reasons are: system diseases of locomotor system, inflammations, damage caused

¹ S. Golinowska, Integracja społeczna osób niepełnosprawnych. Ocena działań instytucji, Warszawa 2004, s.19.

² Wł.Dykcik, Wprowadzenie w przedmiot pedagogiki specjalnej jako nauki, red. Wł.Dykcik, Pedagogika specjalna, Poznań 2005, s.15.

³ B.Szychowiak, Wychowanie dzieci niesprawnych ruchowo, w: Dziecko niesprawne w rodzinie, red. I. Obuchowska, Warszawa 1991, s.354

by injuries, cancers. Deformations may appear in various periods of child's life, and sometimes they are born with a visible defect. Defects and developmental disorders may have various scopes. Thus, the reasons of congenial defects and developmental disorders are varied⁴.

General characteristics of the research

The main aim of the undertaken research, carried out in a seminar group by the student Iwona Lewandowska among 11-15 year old participants with locomotor system defects who are gathered in the Association of Disabled Children and Youth "Amari" in Zabrze, was to find out quality of life of the aforementioned group and factors conditioning it. The aim of the association established in 1996 by parents and caretakers of disabled people is undertaking all actions to create optimal conditions of help in raising disabled children, initiating and developing specialist forms of help to parents of these children, cooperation with other organisations and institutions, integrating the disabled children and youth into the environment of their healthy peers. The following research issues were set:

1. Whether and in what way does a type of child's physical dysfunction influence their life opportunities?
2. Whether and in what way do a stay in a hospital and surgeries influence child's functioning?
3. Whether and in what way does a rehabilitation which is performed influence child's life quality?
4. In what way do the place of residence and architectural barriers connected with it influence the life quality of a motor disabled child?
5. What possibilities of education do the children with locomotor system dysfunction have and in what way does this fact influence their life opportunities?
6. Whether and in what way does motor disability conditions the independence of a child with locomotor system disfunction?
7. In what way does the child's physical appearance influence their life attitude and self-esteem?
8. Whether and why having siblings and contacts with peers has a meaning in functioning of a child with motor disability?

⁴ B. Arusztowicz, W. Bąkowski, Dziecko niepełnosprawne z dysfunkcją narządu ruchu, Kraków 2001, s.9.

Characteristics of the researched group

Presented characteristics include the researched group of eight children aged 11-15 with motor disability.

Type of a child's physical dysfunction and its influence on life capabilities

Sebastian – age 14. First pregnancy, its course without complications. He was born in the eighth month of the pregnancy, his mother got a haemorrhage, breech birth, evaluation with the use of Apgar test for 4, body weight 0.900 kilogram, body length 50 cm, he had difficulties in breathing. Proper development, in the third month of his life he raised his head properly. In the fifth month a child “strained” himself, he did not raise his body to sit, diagnosed four-limb, spastic Infantile Cerebral Palsy. Sebastian properly reacted to auditory and visual stimuli.

Marta – age 11. Pregnancy ran correctly, without complications. She was born in the ninth month of the pregnancy, natural labour, evaluation with the use of Apgar test for 7, body weight 1.950 kilogram, body length 52 cm, initially she developed properly, the reflex of raising her head appeared in the third month, her parents noticed small activity of her legs, the child often cried and would not sit. Hip bone and acetabulum defects were diagnosed, the child also has side scoliosis. After medical consultation the child was prepared for scoliosis surgery.

Monika – age 12. First pregnancy, ran correctly till the seventh month, when the mother got a haemorrhage and reached a hospital where caesarean section was performed, the child had an umbilical cord wrapped round her neck, evaluation with the use of Apgar test for 5, body weight 1.300 kilogram, body length 48 cm, first two weeks she spent in an incubator, additionally she had cleft palate, in the first months poor visual contact was noticeable, the child was very excited. When the child was one-year-old four-limb spastic cerebral palsy was diagnosed.

Kasia – age 15. Twin pregnancy (the second child was born dead), she was born with an umbilical cord wrapped round her neck, blue, evaluation with the use of Apgar test for 7, body weight 1.500 kilogram, body length 45 cm, difficulties in breathing, for the first three weeks kept in incubator. Relatively late, when she was about a year old neurologists diagnosed four-limb, spastic Infantile Cerebral Palsy with the dominance of lower limbs, she also had hip problems typical for the infants.

Daria – age 11. Born prematurely and delivered by caesarian in the seventh month of pregnancy, evaluation with the use of Apgar test for 8, body weight 1.900 kilogram, body length 48 cm. Immediately after birth visible meningomyelocele in loins section, what caused paraplegia and dysfunctions in urination and defecation. Due to that condition placed at children surgical ward.

Michał – age 13. Pregnancy ran properly, he was born in the ninth month of pregnancy, natural labour evaluation with the use of Apgar test for 7, body weight 2.450 kilogram, body length 50 cm. Child with visible small meningomyelocele, what caused partial paraplegia and faecal and urinary incontinence. Due to that condition placed at children surgical ward.

Basia – age 12. Born in the seventh month of the pregnancy by means of caesarean section, evaluation with the use of Apgar test for 5, body weight 1.700 kilogram, body length 46 cm. At the age of 16 months Infantile Cerebral Palsy with increased muscular tonus was diagnosed, she also started to have problems with sitting down.

Gosia – age 14. Proper course of pregnancy, born in the ninth month, body weight 2.600 kg, body length 50 cm. After childbirth luxation of the hip joint and when she was 7 week old osteopsathyrosis were diagnosed.

Surgeries and course of rehabilitation.

Locomotor rehabilitation of the children starts at the earliest months of their life, while they are either operated on (as in case of meningomyelocele) or undergo prolonged and often very painful rehabilitation (cerebral palsy). In many cases there are a few or several surgeries which involve frequent and prolonged stay in a hospital far from their place of residence and parents, what is undoubtedly additional stress for them. Every day children spend a few hours on rehabilitating exercises, which are often done till the pain limit. Many of the children move around with a use of crutches or a wheelchair, often they are also in orthopaedic devices such as splints and corsets which limit unrestrained movement. Even if physical condition allows a child to go to school, frequent and prolonged rehabilitation causes frequent absence from classes, what, in effect, leads to loosening emotional bonds with their peers.

Housing conditions and architectural barriers connected.

In a vast majority the children live in blocks where there are no lifts and every day they have to walk up and down the stairs, alone or with a help of their parent. The buildings are not adapted to their needs (narrow corridors and doors). Parents often try to adapt their flats installing bath rails, low, adapted shower cabins with a seat, anti-slippery mats to bath-tubs. Child's room is most often small, with few items of furniture in order to leave place for

movement. The place of residence undoubtedly seems important. Most often the children live in a centre of town or in “green” districts far from noise, what is favourable for independent movements. Most children have access to a computer and possibility to leave home and go outside with accompanying person (Monika, Kasia, Daria, Basia).

Children’s educational capabilities.

Majority of students commenced their education At the age of six by taking kindergarten class and, thereafter, by attending elementary school. It happened that due to frequent stays in a hospital and rehabilitation centre they missed a large number of hours in school and were forced to move to individual system of learning at home. The system in a large degree limited their contacts with their environment, and most importantly with their peers. In most cases, school study was difficult for children, due to their handicap in manual dexterity which made it difficult for them to learn how to write. As a rule they were not accepted in their schools not only by the children but also by the teachers. In many cases schools were not adapted to child with motor disability capabilities, what impeded child’s education in a given school.

Capabilities and limitations in performing physical activities.

The examined group was characterized mostly by disability of lower limbs in various degree. Preserved hand fitness enabled them to perform most of self-service functions such as getting dressed, eating. However it must be added that in most cases the parents helped their children in many functions for a very long time (often till starting by them their school education). The parents presented varied approaches, some of them replaced their children in their activities, as a reason giving their disability, while others practically forced their children to perform independently most of their functions. Most of the children needed help while taking a bath, as entering a bath-tub was a large difficulty for them. Most often children performed minor functions beside self-service functions, and some of them reached a level of physical development which generally enabled them to be independent (Sebastian). Children’s independence was obviously dependant on a type of illness, but also on child’s will and attitudes of their caretakers.

Physical appearance and self-esteem connected with it.

In younger age children did not pay particular attention to their appearance and often they did not notice differences between each other. Often their peers, but also adults did not give them to understand that they are different. Currently, in a period of puberty, when the interest in their own appearance increased in most cases they do not accept the way they look, they (mostly girls) feel worse and less attractive. Sometimes they assume a completely passive attitude towards their appearance and clothes and focus much more on wearing glasses or acne.

Interpersonal communication with siblings and peers.

Most of examined children do not have any siblings and has sporadic contacts with their peers from the family. In one case – of Sebastian – having younger brother enables a certain degree development of physical abilities through competition with the younger brother, what is largely important for a sick child. Unfortunately, there are cases when sibling rejects sick child. Relationships with healthy peers at school are being dependant on physical potential of a child. However, often due to their disability sick children are withdrawn and they avoid contacts with healthy peers.

Conclusion

Undoubtedly period of hospitalisation and process of rehabilitation influences negatively quality of child's functioning, however in many cases enables patient to reach new developmental opportunities. Surgeries and connected child's immobilization for a long months in plaster or orthopaedic devices influences negatively their physical, psychical and social comfort. It is also needed to remember that a period of hospitalization and process of rehabilitation are dependant on the attitude towards the disabled, because, as G. Cloekes's examination shows, people with physical lacks are commonly judged more negatively. The way a child will be able to function depends thus on very large number of factors

References:

1. Arusztowicz B, Bąkowski W, Dziecko niepełnosprawne z dysfunkcją narządu ruchu. [Disabled Child with Locomotor System Dysfunction] Kraków 2001.
2. Balcerzak-Paradowska B, Sytuacja osób niepełnosprawnych w Polsce. [Situation of Disabled People in Poland.] Warszawa 2002.
3. Dykcik W, Wprowadzenie w przedmiot pedagogiki specjalnej jako nauki. [Introduction to a Subject of Special Pedagogy as a Science.] ed. W.Dykcik, Pedagogika specjalna, Poznań 2005.
4. Golinowska S, Integracja społeczna osób niepełnosprawnych. Ocena działań instytucji. [Social Integration of the Disabled. Evaluation of the Institutional Actions.] Warszawa 2004.
5. Kościelska M, Aouila B, Człowiek niepełnosprawny. Sprawność w niepełnosprawności. [Disabled Man. Ability in Disability.] Bygdoszcz 2003.
6. Majewicz P, Obraz samego siebie a zachowanie młodzieży niepełnosprawnej ruchowo. [Picture of Oneself and Behaviour of Motor Disabled Youth] Kraków 2002.
7. Speck O, Niepełnosprawni w społeczeństwie. Podstawy ortopedagogiki. [The Disabled in the Society. Basics of Ortopedagogy.] Gdańsk 2005.
8. Szychowiak B, Wychowanie dzieci niesprawnych ruchowo, w: Dziecko niesprawne w rodzinie. [Education for the Motor Disabled Children. In: Disabled Child in a Family.] ed. I. Obuchowska, Warszawa 1991.