SOCIAL CONDITIONS OF THE EXISTENCE OF A POLISH FAMILY WITH AN INTELLECTUALLY DISABLED CHILD

In this article the author examines the socio-economic problems of families, in which grows intellectually disabled child, using the results of the researches carried out in Poland in the period from 1990 to 2008. According to the results of numerous studies major obstacles in the process of socialization of intellectually disabled children are not only violations of intellectual development, but also the socio-economic situation of the family and the stereotypes that prevail in the society. Lack of education and lack of the necessary skills of parents of the intellectually disabled child leads to a lack of job and hence a deterioration of living conditions. On the one hand low standard of life of these families, as well as characteristics of the disease of the child, and a certain amount of social and economic assistance from the state on the other hand provide certain stereotype about these families, and often this stereotype is painted negatively. The existence of such stereotype markedly exacerbates socio-economic status of the family and the possibility of changing it, what subsequently can lead to social isolation. Given these facts, the author stresses the need for continuous monitoring of the socio-economic status of families, in which intellectually disabled child grows.

Key words: intellectually, disabled, child, socio-economic, condition, family, existence, Polish

Introduction

Part of the public is convinced that we live in magical, fairy-tale times, where people in need are cared for, the hungry are nourished, children learn and most adults work. Unfortunately, this is the utopian view of the situation. There are quite frequent, certain stereotypical social beliefs that a person affected by disability has too many rights and allowances. One often hears the opinions on “a waste of public funds” to support people with disabilities, which after all can be better used.

One of the surveyed mothers countered the attacks on relief enjoyed by her disabled son in the following way: “if you think I have special privileges, take them along with my disability” Cholewa-Selo, 2004: 37).

Mental retardation - social and theoretical context

When introducing the problems of economic functioning of families with a disabled child, we must point out shortcomings in a systematic statistics of these families in Poland. The number of people with disabilities, their economic situation, types and causes of disability are given the very approximate, and may differ from the actual situation.
According to the World Health Organization (WHO) there are about 450 million disabled people in the world, representing 10% of the total population. In Poland, the number of people with disabilities exceeded 5 million (in the year 2002 – 5.4567 mln representing 14.3% of the total population). Every seventh Polish citizen is a person with a disability.

The concept of disability can be contacted by a twofold meaning. First, it is viewed as impairment of a functional nature, occurring within the physical or mental activities of a person. Then the results achieved by a disabled person are below those reached by a person widely regarded as normal. It refers to the use of the term “mental disability”. This term, however, may have other, more common understanding. In the second sense of the term, “disability” is treated as downgrading of a person by treating him/her as worse, comparing to others. Following J. Kostrzewski (1978: 51), we can adopt the definition that mental retardation “is significantly lower than the average overall level of intellectual functioning in association with impairments in adapting, related to changes in the central neural system”.

Among the determinants of mental retardation, primarily mild, there are three factors:
1. the existence of changes (structural or functional) in the central neural system;
2. the influence of pathogenic factors on the local community or family
3. the existence of changes in central neural system with the simultaneous influence of pathogenic factors of family environment (Obuchowska, 1991: 199-233).

The situation of families that raise children with intellectual disabilities

The birth of an intellectually disabled child dramatically changes the existing structure of its family and the functions it performs. A number of stress factors, which are inherent in the daily care of the child and which lead to burnout, may occur. These include: a heavy workload, falling into a routine, loss of social contacts, lack of rest, social isolation and feeling lost in the meaning of life. I.M. Marcysiak (1999) has studied a group of 40 mothers of children with disabilities and a comparative group of 40 mothers of children without disabilities. Conducted in and around Warsaw in 1998, Marcysiak’s research demonstrates that mothers of disabled children are prone to higher stress and anxiety levels than their counterparts in the control group. The author concludes that such a state can result from “their anxiety over the child’s future, increased sensitivity to public opinion, sense of guilt and feeling helpless when
confronted with child behavior problems. This in its turn reduces their competence as parents” (1999: 263).

Child’s disability usually causes the economic situation of the family to deteriorate. Most mothers give up their jobs until the child goes to kindergarten. As a result, mothers rarely fulfil their professional ambitions and the family budget becomes dependent on one salary. The father takes extra work to maintain the current standard of family living. In practice, it can lead to marital conflicts. The woman is left alone at home with a sick child, the man feels overwhelmed and tired of his job. Furthermore, parents’ social life is limited. But at the same time, the parents may feel happy having a disabled child. According to the classification proposed by Galkowski (1979: 81), after the stage of shock the emotional crisis appears followed by adapting to the new situation. Thus, there comes a moment of reflection, thought, then apparently true and finally real constructive acceptance of the child. Then the family is able to create good conditions for development and rehabilitation of the child. And the child, while in the friendly, safe and loving family environment, will be able to get and develop the best of their ability skills necessary for social functioning.

Social, system and political transformation in Poland after 1989 as well as the effects of the global crisis worsened the economic situation of many families. This fact was noticed by Korzon (2004). “One of the negative effects of social and economic transformation initiated in Poland after 1989 is, among others, the danger of being of social groups who require special care, as their income level and social status decrease” (2004: 96). The areas of poverty enlarge, which puts families with intellectual disabled children in a difficult position. Deterioration of the overall labour market situation and the effects of the global crisis result not only in a lack of new jobs but also in the release of former employees. Family expenses continue to grow.

Many disabled people have been pushed to the side of working life by giving priority to employment and able-bodied, educated people. The subject of professional activity of the disabled people has been taken up by Konarska (2008: 85), who claims that “Liquidation of companies, lack of prospects for the future, struggling with tough living conditions is for them just another side of hopeless existence, which is a complement to their lives marked by the stigma of disability anyway.”

In the opinion of Ziemska (1980), unemployment leads to disturbances in family life. The family becomes the arena for resolving tensions associated with lack of work and possibilities of satisfying the needs of its individual member. This leads to problems in the implementation of the basic functions of the family, mainly function of socialization, service and care, procreation and economic or psycho-hygienic function (1980: 234). Children suffer the consequences, regardless of whether they are disabled or able-bodied. Kawula (2002: 156)
emphasized that children, as a result of these disorders, are unable to fully develop the physical and emotional sound of their personality, which can lead to difficulty in functioning in adulthood and lack of skills in performing certain social roles. Family relationship disorders as a consequence of unemployment help to increase the number of divorces and family leaving.

Kazanowski presented a review of research conducted in the 1990s on the economic situation of families having children with slight impairment in Poland. In the summary, the author concluded that the economic situation of families with disabled children is worse than families with children without disabilities. The budget was generally judged to be insufficient to meet the needs of the family. The level of material conditions was assessed very low. Thus, children often used different types of material assistance. Families often lived in low-standard apartments without a bathroom, toilet and hot water. A child rarely had a separate room, often did not even own a place for doing homework and even sleeping. Homes were often too tight, wet, cold and not very clean (2003: 52).

**The state of research on the financial and economic situation of families with intellectually disabled child**

The economic situation can be the condition determining not only a good start and development of a person, but also the factor having influence on the social segregation. On the basis of her own research, Borzyszkowska (1997) was looking for the connections between the social isolation and the financial situation. By analyzing the opinions of parents having children suffering from slight intellectual impairments (870 families) she made a conclusion that the society secludes itself from the disabled for the following reasons:

1. the socio-economic status is usually lower in comparison with other families, which is a result of the family’s difficult financial situation and poor housing conditions
2. scant financial resources determining the family’s social position, which is not approved by the society
3. the fact that the family belongs to the working class, the members of the family are not well-educated and, first of all, they do the job of small value
4. their intellectually disabled child does not meet the demands of the society and because of its restricted mental abilities it cannot have impact on their healthy child (Borzyszkowska, 1997: 58)

Łaś (1992) analyzed the family situation of 21 children with slight intellectual impairments between the age of 9-17. She revealed the following phenomena: most often the children came from families with a great number of children, which were mainly complete
families. However, quite often the fathers had criminal records and served penalty of deprivation of liberty in reformatory. She also noticed the tendency to spend money unreasonably in these families. Frequently, children did not have their own place to do the homework (1992: 67-75). The author stated that half of the families lived in the conditions not conductive to the rehabilitation (very low parents’ earnings, lack of the basic meals at home, shortage of clothes for every season, as well as own toilet appliances and school accessories, lack of sources for pocket money) (Łaś, 1995: 77-84).

Due to the findings of his research, Kościelak (1996) stated that the characteristic of intellectually disabled children’s family environment was determined by their low financial status. The flats were most often one or two roomed, frequently without bathrooms and hot tap water. The majority of the mothers had elementary education and worked as unqualified workers, whereas the majority of the fathers had vocational education. A predominant number of families were ones with many children, the average number of people in the family amounted to 6.2.

The family environment of 298 schoolgirls between the age of 10-17 attending the special primary school was examined by Gawlik (1995). Almost the whole group of girls came from the families of workers (98.7%), whereas only 1.3% came from the intellectual families. The dominant kind of education among the fathers was the vocational education (57.4%) and among the mothers – elementary education (60.7%). 70% of the girls were brought up in complete families, 14% - in incomplete families, 2% - in reconstructed families, 2% - in foster families, the remaining number of children – in an orphanage. Unfortunately, almost half of them had contact with the pathology of family life (47% of the examined environment, where alcoholism applied to 28% of homes, social negligence – 13% and demoralization – 6%). The unemployment applied to half of the mothers and to 16.4% of the fathers (1995: 11).

The realization of caring and educational function in the families having children with slight intellectual impairments was examined by Kozubska (1995). She examined 90 families with children suffering from slight intellectual disability attending lessons in forms I-III. Her findings were alarming, since 21% of the fathers and 53.8% of the mothers did not work, 27.5% of children did not have their own bed, 38.8% of children did not have their place to learn. Their parents mostly had elementary and vocational education. In 75% of the families having slightly intellectually disabled children, the income was not enough to satisfy the basic needs (food, clothes, the school accessories). The author also draws attention to the overcrowding in the examined families’ flats (Kozubska, 1995: 29-30). The next Kozubska’s research (2000) included 120 families with slightly intellectually disabled children attending classes in forms I-III of special primary school and 120 families with children developing in a normal way. The complete families made up 75.8% of the examined families with slightly intellectually disabled children. Among these families there were more families broken as a result of a divorce. The amount of children in the families with slightly intellectually disabled
children was significantly bigger that in the group of the families with children developing in a normal way.

The author of the next research was Otrębski (1997). His research was carried out in the families of 160 slightly intellectually disabled children attending classes in primary or vocational schools. Supposedly, parents had the kind of education, which was not competitive on the labor market. Over 40% of slightly intellectually disabled girls’ parents had elementary education. The author drew attention to difficult housing conditions, lack of convenient conditions to do the homework, low income and big amount of children in these families.

Barłóg (2008) examined 180 parents of children with slight intellectual impairments from the region of Rzeszów in the school year 2006-7. One of the objects of her research was the families’ financial situation. According to the analyses, the examined parents have mainly elementary or vocational education, which, of course, has an impact not only on the low economic family status, but also, as the author suggests, on parents’ insufficiency in fulfilling their caring and educational functions. Moreover, it contributes to occurrence of pathological behaviours. Almost half of the examined families did not have jobs (45%). Mainly the fathers were those who worked. Among the unemployed there were 45% of the mothers. The group of working parents occupied low posts, thus the family’s income was insufficient to fulfil the demands of the family members, especially of the intellectually disabled child. Only 4.4% of parents went on holidays with their children annually (2008: 222-226).

The purpose of Minczakiewicz’s research (1995) was to get familiar with the situation of intellectually disabled child perceived in the light of its position in the family. The population made up 80 children with mental impairments between the age of 8-12, including 40 children with slight intellectual impairments and 40 children with moderate and considerable mental impairments, as well as their parents (67 mothers and 13 fathers). The author observed that most of the families with children suffering from slight intellectual handicaps applied the educational model, which can be called “social circle” (mutual respect, help and cooperation). In the families having children with more severe mental impairments the most common was so called “central model”. The overprotection and excessive attention are typical of this model. Obviously, the research confirmed the situation described above, concerning the statement that intellectually disabled children between the age of 8-12 perceive themselves and their position in the family in the light of their parents’ and siblings’ attitudes (1995: 51-60).

Wojciechowski’s research (1993: 45) produced following conclusions: 14% of the families are educationally insufficient (they are dysfunctional). Only in few exceptions (5.25% of families) parents accepted the fact that they have intellectually disabled child. 22% of parents claimed that they understood their child’s situation and that they accepted it completely, 32% did not accept this situation completely, even though they did not negate
their child’s developmental dysfunctions, 46% of parents were not interested in their child’s state of health.

Conclusions

It is easy to emphasize positive changes that take place in the social reality of the disabled persons, e.g. concessions, parking spaces and nursing allowances. Such an account is devoid of unpleasant details, tough. It should be mentioned here that employment chances for the parents of intellectually disabled children prove particularly bleak. Poor qualifications seriously affect their job opportunities.

It is necessary to regularly examine intellectually disabled children and the social-economic situation of their families. The deteriorating standard of living of these families may lead to their social isolation. Despite the fact that society conforms to an idea of equal opportunities, apart from removing architectural obstacles, it does very little to improve the life of families that raise intellectually disabled children. Our mentality is perhaps yet another obstacle. It is only apparently that mentally disabled persons have a right and not just a privilege to be integrated into society.

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Социальные условия существования польской семьи с умственно отсталым ребенком

Резюме

В данной статье автор рассматривает социально-экономические проблемы семей в которых растет ребенок с ограниченным умственным развитием, используя результаты многолетних исследований, проведенных в Польше в период с 1990 года по 2008 год. По результатам многочисленных исследований главными препятствиями в процессе социализации детей с ограниченным умственным развитием являются не только нарушения умственного развития, но также социально-экономическое положение семьи и стереотипы, преобладающие в обществе. Недостаточный уровень образования и отсутствие необходимой квалификации родителей такого ребенка ведет к отсутствию места работы и, следовательно, к ухудшению жилищных условий. Низкий стандарт жизни таких семей, а также особенности заболевания ребенка, с одной стороны, и некоторый объем социально-экономической помощи от государства, с другой стороны, формируют определенный, зачастую негативно окрашенный стереотип о данных семьях. Существование такого стереотипа заметно усугубляет социально-экономическое положение семьи и возможности его изменения, что в последствии может привести к социальной изоляции. Принимая во внимание данные факты, автор подчеркивает необходимость постоянного мониторинга социально-экономического положения семей, в которых растет ребенок с ограниченным умственным развитием.