**IMPACT: International Journal of Research in Applied,
Natural and Social Sciences (IMPACT: IJRANSS)
ISSN(P): 2347-4580; ISSN(E): 2321-8851
Vol. 4, Issue 11, Nov 2016, 175-180**

FROM EXCLUSION TO PARTICIPATION- QUALITY OF LIFE OF A SMALL CHILD WITH A DISABILITY IN POLAND CASE STUDY

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ABSTRACT

In Poland social assistance benefits are granted for families, however poverty does not touch its members equally. It affects twice more frequently children than their parents or grandparents. The study presents the situation of families with a child with autism (autism spectrum disorder), which in particular often requires special support against social exclusion.

KEYWORDS: Poverty; Child; Social Assistance; Autism; Exclusion

INTRODUCTION

REASONS AND AIMS OF THE STUDY

In the modern world the quality of life usually refers to the possibility of full participation in social life. It is important and essential for individuals especially in the development phase - children and young people- and gains importance if they are individuals with any of the deficits.

The quality of life of young children with intellectual disabilities has been the subject of reflection of a number of researchers. In the case of small intellectually disabled children the quality of life is particularly important because of the need for early intervention and taking related opportunities to reduce the existing gaps to the minimum. The problem is important and there is little empirical research on preschool children with disabilities. This is determined by several factors: difficulties in communication with such young children, necessary consent of parents or guardians for participation in a study, and finally a relatively small scale of the phenomenon. Children with intellectual disabilities represent only a small proportion of the disabled population[1]. Nevertheless the marginalization of the problem and the difficult situation of their families cannot be allowed. Contemporary Special Education proposes inclusion of a disabled individual in society Błeszyński, 2010, 2013; Speck, 2011)[2]. The priority of the European Union is to include a family with a disabled member in society. Declaration of the Rights of the Child requires the state to care for the quality of life and satisfy the need of development of each and every child.

This article and research result spresented in it are an attempt and encouragement for joint reflection on the problem. In Poland, children are a total of approximately 18% of the population, including children with disabilities 3%

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[1] Therefore, the research quantitative, not only because of the size of the population, but also because of the nature of the problem.

(184.8 thousand). Out of this group one in five children has a diagnosis in the field of neuro developmental disorders, disorders of communication (*Children in Poland*, 2015).

METHODS - EMPIRICAL ANALYSIS OF THE COLLECTED RESEARCH MATERIAL

Family Background and Socio-Economic Situation

The research involved a small group of children with autism (N = 40) who attended a special kindergarten. Researchers were interested in the quality of life and the socio-economic condition of children's families. All information has been obtained from adults (parents and teachers).

Low quality of life of children in Poland is the actual state and in the case of a child with a disability it is significantly worse.

One of the reasons of poor quality of life is single parenthood, when only one parent needs to ensure resources to support the family and fulfill educative functions. It often happens that mothers are abandoned by the fathers of disabled children. Meanwhile, in the group of more than 90% of cases were natural biological families. 3% of the study subjects were rebuilt families.

Another characteristic of the surveyed families was the place of residence. In Poland there are more children with disabilities living in the city (*Children in Poland*, 2015). In completed research, these proportions were equal. Half lived in the countryside and in small towns, half of them in the larger cities).This issue is important since a greater metropolitan area gives incomparably better chance for access to rehabilitation and diagnostics and even to specialized care and education. And in case of parents it is significantly easier to find employment. In the studied families, 90% of men and only nearly 20% of mothers worked. In the area where the research was conducted, unemployment was quite an important issue and relevant for many families. In contrast, a low rate of labor force participation of mothers resulted from the model upbringing in the family. It is common for families with a disabled child that mothers do not work to devote themselves to caring for children.

The Level of Satisfaction of the Needs of the Children in a Nationwide Context

Properly conducted processes of inclusion in the social life aim to equally satisfy two categories of needs the needs of existence and development. Without providing essentials of life, there is no possibility of continued existence of a child, but without satisfying children's need of development, there is no chance for social participation and so for leaving the vicious circle of poverty.

Fortunately, people with disabilities, especially the respondents of the study were not in such a difficult situation. More often than others, they were guaranteed appropriate nutrition. More often than other Polish citizens, they lived in heated homes and had the resources to meet unexpected expenses. Unfortunately, less often than other Polish families, they could afford to buy a car. And a car would be the extremely helpful in their life situation.

Table 1: Deprivation of Needs of Respondent Families Compared With Polish Families in General and Polish Families with at Least One Disabled Family Member in Percentage

Type of Need	GUS (Central Statistical Office) Data		Ownresearch
	Polishfamilies	**Polish Families With at Least One Disabled Member**	**N= 43**
Is it affordable for a family to eat meat, fish or vegetarian equivalents every other day?	86,9	81	**91**
Is it affordable for a family to heat a household as needed?	50,8	81,2	**88**
Can a family afford to cover unexpected expenses?	50,8	40,1	**49**
Does a family pay mortgage, loans and other payments connected with accommodation without delay?	12,2[a]	14,9[a]	**12**
Does a household lack a car for financial reasons?	11,0	14,9	**14**

Note: all the questions included a phrase „ in the last 12 months" (*The living conditions of families in Poland* 2014)

b / development needs

During the study parents of the children were asked whether their child can participate in additional paid learning and developmental activities such as swimming, playing an instrument, membership in youth organizations, etc... In such a favorable situation there were only 1/3 of them (35%). Comparing the situation of the tested children to all children in Poland, only 15% of them could not participate in such activities for financial reasons. 85% of children had access to this type of activities according to a nationwide survey (Szukiełojć-Bieńkuńska, 2011, p. 7).

The difference is drastic. Such a situation could result from the specific nature of disability as well as, what needs to be emphasized once again, the difference in sizes of compared groups. Probably these variables can be the cause of this thesis and other differences related to satisfying development needs. 79% of autistic children have access to the equipment for playing outdoors such as a bike or a skateboard. The figure for all Polish children is 94 %(Szukiełojć-Bieńkuńska, 2011, 7).The same situation involved access to toys and educational games relevant to the age and popular among their peers (the figures were 86% of survey respondents and 94% of Polish children in general)(Szukiełojć-Bieńkuńska, 2011, p.7).

Next category of development needs is needs for socialization which in the case of children, especially children with autism are very important. Inviting peers home, celebrating different occasions and spending holidays away from home were adopted as indicators of satisfaction of the need for socialization.

In the study, 14% of the respondents did not have the funds to finance participation in school trips and other events organized by the school and such a situation concerned 6.4% of all Polish children - which is twice less. Meanwhile, the index of the possibility to celebrate special occasions such as birthdays, name days or religious holidays was similar. In both groups it was high - more than 90% (93% for children with autism and 94% for the entire Polish population of children (Szukiełojć-Bieńkuńska, 2011, 7).

The key to socialization and development, also biological development is the ability to relax and go on holiday. Every third Polish child (33%), and every other (44%) child from the study group could not benefit at least once a year from a one week holiday (Szukiełojć-Bieńkuńska,2011, 7).The existence of such a serious deprivation of one of the essential needs in such a large proportion of Polish children, including the disabled, is a worrying situation. The right for relaxation is one of the inalienable needs of the child (adults as well) guaranteed by the Convention on the Rights of the Child (art. 31 par. 1).

Table 2: Deprivation of Development Needs of Respondent Families Compared with Polish Families in General and Polish Families with at Least One Disabled Family Member in Percentage

Question	Polishfamilies	Own Research N - 43
Is it possible for a child to invite peers home to play and eat together?	93,6	**86,0**
Is it possible for a child to celebrate special events like birthdays, name days or religious holidays?	91,0	**93,0**
Can a family afford to organize a weekly holiday once a year?	66,7	**56,0**

Analysis based on own research and A.Szukiełojć-Bieńkuńska (2011a).

Sources of Support for Children and their Families

In modern democratic societies, there are different ways to support citizens in difficult situations. In Polish conditions it is social assistance provided by state agencies, NGOs and churches, assistance and support provided within the framework of individual support and assistance of family members. The study showed that besides the assistance provided by the specialized agencies of the state, which was received by more than 40% of the respondents, the second most important entity granting support to children and families (every fourth) was help coming from other people and institutions, and in the third place were the kindergartens, which the studied children attended (it related to every tenth child).

In addition to the diagnosis of the existing state of affairs, the surveyed families were asked whom they expected such assistance from. More than half of them awaited the help of state as an institution. Only a small proportion of them (below 10%) expect assistance from the closest family. It is significant that almost half of the respondents did not expect help from anyone. At this level of the research it cannot be determined what causes such a situation, the lack of need or a high level of mistrust.

CONCLUSIONS

The quality of life of small children with disabilities in terms of socio-economic development is not frequently researched. Meanwhile, the quality of life at this stage of development depends on the implementation of the paradigm of modern special education - social inclusion (more in Orłowska, Błeszyński 2016). It should also be acknowledged that in order for the surveyed children to reach the optimum quality of life, their families bear the additional burden of - rehabilitation and care. This often results in the necessity of the parents to resign from work- usually mothers. In this situation, the economic shortage of the family of a child with a disability deepens. Hence, among other things, the study revealed areas of deprivation of needs and especially the development needs.

The authors of this study wanted to draw attention to the distance that divides families with disabled children from other families without disabled children. Additionally, the research also revealed some overlap – e.g. deprivation of the need of rest. This may indicate that this is not a characteristic of families with a disabled child but the overall "specificity" - a characteristic of all Polish families. It does not justify by any means the existing situation.

This study, although of a very limited extent, is one of the first steps for diagnosis of the situation of difficult problems such as exclusion of children with intellectual disabilities and identifying areas of deprivation. Knowing the situation, countermeasures can be undertaken. Problems connected with acquiring social skills by children with autism and intellectual disabilities were tackled by other authors (Mohammed, Mostafa, 2012 pp. 32 – 43; Hasanin, 2015, pp.: 10 – 15.). However, this study was designed to show the deprivation, influencing the quality of life of children and families who are experiencing problems of social functioning of people with autism spectrum disorders.

The authors appeal for discourse and the exchange of experiences between researchers and practitioners. It is important to create optimal ways to support social participation as an important factor influencing the experienced quality of life of a disabled child.

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