

## BETWEEN SOCIAL INCLUSION TO EXCLUSION - DIFFERENCES IN THE QUALITY OF LIVES OF INTELLECTUALLY DISABLED CHILDREN

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### ABSTRACT

The work undertaken was a problem situation deprivation needs of young children with disabilities caused autism. The research was conducted on a group of 43 families in Poland. Our findings can be generalized.

Contemporarily, disability is perceived as one of the important factors of exclusion. Reduction of developmental or existential needs permanently excludes not only today, but it denies any chance for tomorrow.

**KEYWORDS:** Autism, Intellectually Disability, Deprivation, Inklusion

### INTRODUCTION

More and more frequently, issues of families with a disabled child are discussed in the literature. In the last fifty years, most of the attention has been devoted to broadly understood classification, analysis of individual cases and disability. Recent years have introduced us in a wide range of analyses of disability in its aspect of etiology, performance of supportive (therapeutic) activities and functioning of such people in the environment.

An important element in the development of the theory of pedagogy was a departure from the clinical perception of disability, for the benefit of locating a disabled person in the society. Different trends, starting from selection, attempts of integration, up to inclusion, do not only show the evaluation of disability in a significant way, but they also place disabled people in the society (Dykcik, 2005; p.41 - 53). M. Orłowska has attempted to present the meaning and needs of research on the social perception of people with disabilities. (2013, p. 37 - 47).

Dynamic political and economic changes influence cultural evolution of disability. Additionally, demographic changes and social migration highlight the problem of disabled people in the society (cf. Błeszyński, 2010, p. 65-68). Attempts to shift the responsibility for these individuals to the state have caused serious economic and political problems. The attention has been paid not only to the social economics of the perspective on disability, but also to the attempts aimed at enabling those people who, despite their disabilities, make up an important element of the functioning of societies – to accept their diversity, evoke awareness and social responsibility.

### Pervasive Developmental Deficits

*Pervasive developmental deficits* is a term used in relation to the occurrence of disorders associated with symptoms characteristic of autism. Since the appearance of DSM - IV (*Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition*) published by the American Psychiatric Association, Washington DC, we observe the

introduction of the term: *Pervasive Developmental Disorders (PDD)*. The undergoing changes in the DSM 5 show autism as a holistic developmental disorder (PDD), also known as autism spectrum disorders (ASD).

Changes are more specific, credible and relevant, but more rigorous. It is anticipated that there can be more problems in diagnosing high functioning people with autism spectrum disorders. Undoubtedly, these changes will particularly affect families with children diagnosed with autism, both in the availability of care and support, as well as functioning of people with such a disorder in adulthood.

## **POVERTY AS A SOCIAL PROBLEM**

The concept of poverty has changed its meaning and scope over time. From the attribute of *sacrum*, it has become the foundation of social exclusion and the reason for stigmatisation. The comprehension of poverty is also multi-dimensional. In modern literature prevails the concept that it triggers a short, incomplete participation in social life. Ruth Lister who has researched the issue (2007, 21 et seq.) distinguishes its two categories. The first concerns intolerable deprivation and refers to biological needs of human existence. The second focuses on the relational and symbolic aspects. These refer to human participation in social life. A similar viewpoint is increasingly manifested by numerous agendas of public life, which examine the level and scope of its coverage – e.g. Eurostat. Obviously, in the public circulation, there are many types of measuring poverty and deprivation. They are created for the purpose of studying the phenomenon by different bodies and refer to their different needs. Typically, unacceptable deprivation is associated with the metrics, which relate to the biological minimum, commonly referred to as destitution. It is identified with satisfying only the needs that cannot be “put off for tomorrow”. In contrast, the level of deprivation that prevents from full participation in social life usually refers to the indicators, e.g. minimum subsistence level. Both indicators are separated by significant economic distance and different in their approach to the problem.

Regardless of the measures and their indicators, the problem is scarcity and poverty of significant proportion of children in Europe and around the world. This phenomenon is particularly dangerous due to the so-called remote effects of poverty, i.e. those effects, whose consequences are borne by an entity and the entire society in the long run. The entity is not only impaired in the performance of future social roles, e.g. becomes a blue-collar worker due to poor education, chooses low-paid occupations or has no professional qualifications, but also because of deficiencies in the psycho-somatic development, making it impossible to catch up with others. Regardless of the losses incurred by individuals, we should not forget about the loss experienced by the society in the axiological and economic area – i.e. the loss of social and economic potential.

The scale of poverty among children is significant and it exceeds the level of deprivation for other age groups. The statistical data in Table 1 refers to the poverty of children in the new and old EU countries. It reveals that, according to the EU-SILIC coefficient (comparable with the subsistence level rate), in 2010 more than every fifth Polish child lived in poverty, while according to the relative poverty rate (50% of the median) - more than every tenth child. The over-representation of children in the group of poor people is widespread and affects many countries (*Yearbook of International Statistics in 2012*).

The proportion of disabled children experiencing deprivation needs is significant. Therefore, we can discuss the problem as a social phenomenon.

## RESEARCH

The situation of children in Poland and other new EU countries is extremely difficult, the more that institutional social welfare in Poland refers to the family, and not to its individual members. Hence, the issue of a child is often neglected by professional social services (more: Orłowska 2010). Scarcity is one of the important factors of social risk. Disability is also such risk. Therefore, in the case of researched children, we face accumulation of exclusion factors.

We have been interested in what the situation of families with an autistic child looks like - how they cope in life and what is the level of deprivation of their needs. These families do not only have to satisfy all the essential needs of the existence and development, but spend money on rehabilitation or compensatory classes. Unfortunately, there is no statistics showing the level of life of children, especially such young ones, with disabilities.

The research was conducted in 2013 for the Kuyavian-Pomeranian Voivodeship and it included 50 families, 43 of which met all the criteria. The premise was to have a child diagnosed with autism and permit us to hold an extended interview. Among the interviews, 7 were rejected, 5 were not full, in 2 cases parents withdrew their consent. The main group were families, in which the children were in preschool age (5 - 6 years), preparing to attend primary school.

The research was conducted by means of EU – SILIC exclusion coefficients used by Polish (CSO) and international (EUROSTAT) statistical and research (UNICEF) institutions. The adoption of such a research formula allows us to refer the results to a broader research background, and above all, guarantees the standardisation tool. The study uses classifications and questions included in the EU-SILIC coefficients, concerning deprivation of the child and its family's needs. Only the questions about the satisfaction of basic needs, which is food meals, have been developed. Such a decision was influenced by a common consciousness of deprivation experienced by children without disabilities. This condition was primarily suggested by non-profit institutions (Orłowska, 2010; *Hunger and malnutrition...*, 2013, and more in Orłowska, Błeszyński 2016).

### Characteristics of the Study Group

Due to the fact that most of the children attended kindergarten - parents decided about the time and scope of care during their children's stay in this institution. The determinants included: the wealth of parents or guardians, place of residence (some of these families drove children for classes from the distance up to 30 kilometers), as well as the time they could devote (employment) and the possibility of family support (primarily, grandparents in the growing area of the child).

The structure of the study group. The study involves 43 families, in which one of the children has been diagnosed with autism. In my previously conducted research (Błeszyński, 1998), families with autistic children had a constant structure. Divorces were rare. A study conducted in 2013 showed a significant change in the structure and functioning of families with a child with autism.

This is a typical distribution in the case of autism, since most publications provide a ratio of 3 boys and 1 girl, which directs many authors to search for the etiology of autism in genetic factors.

In the present study, attention should be paid to the fact that the researched group is not homogeneous. A significant group were married people (37 - 86%) caring for a child, cohabitants only in one case (2%). Three (5%) children with autism were looked after by guardians, in this case, grandparents (3 - 5%), because biological parents had gone abroad for work purposes. In most families, children with autism had siblings (24 - 56%), which should be considered

an important and positive trend.

In my previously conducted research (studies from the years 1992-1995 - 20 years ago, cf. Błeszyński, 1998, p. 104), the structure of families was different, only one case out of 55 families was a single mother with an autistic child. There were usually big families, and the coefficient for the predominant trend was higher than the overall for 1.8 (in the surveyed households the coefficient was 2.4, while in other families 1.8, cf. Błeszyński, 1998 s. 105). Frequently, parents who have an autistic child, fear the possibility of another child with autism (and other disorders in development) or they enumerate functional and financial reasons (they are aware of care and education difficulties, limited financial resources, as well as they have concerns about the fate of their children in case of repetition of disorders)<sup>1</sup>.

The vast majority of children lived in two categories of agglomerations: the countryside and towns with more than 100,000 inhabitants, which in the case of the country was significantly associated with the limited availability of specialised care and therapeutic support. Many parents' search for work was determined by a place of assistance for their child.

### Securing Basic Needs

The basic needs of the surveyed involve biological needs.

#### Food

The primary need is to secure food in sufficient quantity and quality, necessary for proper mental and physical development of the child. The basic question in the questionnaire were the principles of serving meals, according to the dietary recommendations - staggering. Securing a minimum of three meals a day (N= 43): no - 12% and yes - 88%. As results from the table, the vast majority of families secured at least 3 meals a day. In the case of 12% (5 children - 2 boys and 3 girls) lack of 3 meals a day was associated with the lack of hunger (1), as well as commuting, and thus having dinner and supper in one (4).

Most parents did not answer the question about the served meals. Generally, the lack of answer to the question was explained by the fact that the type of meals and menu were related to the organisation of the day, resulting from the rhythm of work and therapies.

**Table 1: Type of Meals the Lack of Meals (N = 43)**

|                            |            |
|----------------------------|------------|
| <b>breakfasts</b>          | <b>40%</b> |
| sandwiches to kindergarten | 20%        |
| dinner                     | 60%        |
| supper                     | 20%        |
| lack of answer             | 40%        |

Source: own research.

Most parents drew attention to the fact that therapeutic classes with children and the necessity of earning in many cases determined the type of meal. Children in the kindergarten had set time for eating (second breakfast). There was also the possibility to buy dinner. However, as parents revealed during the interview, combining dinner with supper, and possibly with a dessert. Aspects that they mentioned was a long distance to kindergarten (the need to commute by various

<sup>1</sup> Population of residential area of the child: in the Countryside 43%; town 20 – 50 thousand: 8% Town 50 – 100 thousand 11% town more than 100 thousand 38%.

means of transport), shift-work (the necessity to fit to the type of work), or lifestyle of the family (adopted form of meals). This issue only affected children under six years of age. In the case of eating dinners, most parents answered during the interview.

Most parents pointed to the house, as a place of meals 29 (73%) and kindergarten 13 (33%). Other places included eating dinners organised by charities (and other place 7 [18%] and lack of answer 6[15%]). No answer is not clear, but often serves as the information that dinner is eaten in the family (grandparents, parents' siblings). Doubled results are due to a multiple number of answers (Does at least one meal a day involve meat, poultry or fish? - 33 [77%] and Does he / she eat fresh fruit and vegetables every day? - 28 [65%]).

As evidenced from the information received, 2/3 of the surveyed declared that the daily meal includes meat or fish. The distribution is similar in the case of gender and age of the children.

In the case of fruit and vegetables, the number of children is reduced, which is obviously conditioned by seasons, as well as the price of fruit and vegetables available in stores.

### Leisure and Education

A separate section of study is devoted to leisure activities and education. These issues are important for a child with autism, as they result from the necessity of interactions and the use of social skills. Children with autism have the greatest difficulties in the acquisition of social skills.

Despite providing a child with appropriate toys and teaching aids, it cannot always use them as intended. Toys (e.g. cars, dolls) can be used to set the strings that result from stereotyped behaviours.

**Table 2: Leisure and Education**

| Question  | N= | %  |
|---|----|----|
| Do he / she have books appropriate to his / her age and the level of knowledge and skills (excluding schoolbooks)?                    | 34 | 79 |
| Do he / she have equipment to play outside (bicycle, rollerblades, etc.)?   | 34 | 79 |
| Do he / she regularly participate in recreational activities (swimming, playing an instrument, participation in youth organizations)? | 15 | 35 |
| Do He / she have educational games (at least one per child, including educational toys, playing blocks, board games, computer games)? | 37 | 86 |

Source: own research.

Children with autism were provided the opportunity of using books and the equipment for outdoor activities. Using these means (both books and equipment) mainly concerned boys, as well as it had developmental trends – it increased with the age of the child. In the case of a child's participation in activities outside the kindergarten and school, the number of children is reduced (less than half - 15 - 35%), with a small tendency associated with the age of the child.

Having educational games has the highest results (37 children - 86%), and they are frequently used to play with girls. This has implications resulting from the nature of the disorder, children with autism have good mechanical memory, but difficulty in understanding and complying with the rules of games. Another issue is the possibility of the participation of children with autism in excursions. This is essential, because in the case of ritualistic and stereotyped behaviours, trips

are helpful in acceptance of the changes occurring in the environment.

The vast majority of parents stated that they have the means to organize trips and enable their children to participate in excursions organized by their guardians. These include both trips organised within the school activities as well as therapeutic trips. An important part of family life is the possibility of living together, celebrating holidays and anniversaries, as well as entertaining guests, friends.

**Table 3: Participation in Social Life**

| Question   | N= | %  |
|--|----|----|
| Can he / she invite friends home from time to time, to play together and share meals?                              | 37 | 86 |
| Does he / she have the possibility to celebrate special occasions, such as birthday, name-day or religious feasts? | 40 | 93 |
| Does he / she have financial resources to pay for a week holiday for the family once a year?                       | 24 | 56 |

Source: own research.

An important aspect of therapeutic activities is to organise family environment. As a result of having a child with autism, most families become isolated as a result of disturbances occurring in their child (unacceptable behaviour), necessity to focus on the child's behaviour, as well as difficulty in predicting it. Frequently, families with an autistic child isolate themselves, because they have a sense of lesser value. Earlier, such behaviour was associated with theory, which indicated the occurrence of autism in a child, as a result of abnormal functions within the family (L. Kanner, B. Bettelheim et al.). Now, thanks to the greater social consciousness concerning autism, these families find their place in the society. Openness to contacts with other people, families, as well as common celebrations have become universally accepted style of functioning of these families.

In 2 cases, children did not invite friends to their home for play or have common meals, which can be associated with the fact that these children are not raised in full families, as well as their place of residence does not help them to establish contacts – rural areas). In most centres, multimedia are currently used in the treatment of people with autism. Many nurseries use tablets with educational games during classes. Frequently, they are treated as a form of reward and stimulus to achieve the desired objectives.

More than half of the respondents indicated that they cannot afford a one-week holiday once a year because of the limited financial means. In most cases, they participate in organised therapeutic camps, where children most often go with their mother.

**Table 4: Having a Place to Work (Play) and Use Multimedia**

| Question  | N= | %  |
|---|----|----|
| Does he / she have his / her own place to do homework, spacious and well-lighted? | 38 | 88 |
| Does he / she have an access to the Internet?                                     | 39 | 91 |

Source: own research.

In most of the surveyed families, the child has its separate room, which in the case of children with autism do not necessarily mean good developmental situation, since it impairs the acquisition of social skills (observation of everyday

behaviour, as well as interaction). Most children have appropriate conditions for going quiet, release tension, acquire psychological homeostasis. Also the Internet allows the child to use the multimedia (especially watching cartoons, playing games at this stage – without social interactions).

### Clothing

An important part of human functioning is to provide him with basic elements of clothing that are suited for the needs and seasons.

**Table 5: Apparel and Clothing**

| Question   | N= | %  |
|--|----|----|
| Does he / she have new clothing items (i.e. not all clothes come from second-hand shops)?                                  | 40 | 93 |
| Does He / she have two pairs of property suited footwear (including at least one pair of the so-called all-weather shoes)? | 43 | 98 |

Source: own research.

Parents positively assessed the safety of their autistic children in apparel (clothing). They have met the basic needs in this area. In 3 cases, families received support from close ones, as well as enjoyed the opportunity to make purchases in the so-called second-hand shops. Using a network of second-hand stores stems not only from the affordable price, but also from the attractiveness of the products that can be found in such shops.

### Financial Constraints

In order to determine the level of financial capacity of everyday life, which is the basis of specifying the needs and possibilities of life in the household, general questions were asked. They allow us to present a broader perspective of functioning of a family with an autistic child.

**Table 6: Financial Capacity of the Family**

| Question   | N= | %  |
|--|----|----|
| Can he / she afford to eat meat, fish (vegetarian equivalent) every second day?                              | 39 | 91 |
| Does he / she have the possibility, due to financial problems, to <b>heat</b> the household as needed?       | 38 | 88 |
| Does he / she have the possibility to cover an unexpected <b>expenditure</b> ?                               | 21 | 49 |
| Does he / she have delays in <b>timely payments</b> connected with household, loans or credits?              | 5  | 12 |
| Is there, due to financial reasons, the lack of <b>colour TV set</b> in the household?                       | 5  | 5  |
| Is there, due to financial reasons, the lack of <b>automobile</b> in the household?                          | 6  | 14 |
| Is there, due to financial reasons, the lack of <b>washing machine</b> in the household?                     | 5  | 5  |
| Is there, due to financial reasons, the lack of ( <b>landline or mobile</b> ) <b>phone</b> in the household? | 1  | 2  |

Source: own research.

Analysing the financial capabilities of families with an autistic child in relation to the restrictions they place in

their family environment, most of the respondents pointed to saving money mainly due to limitations concerning the quality of food (meat and fish) and heating. Half of the families feared the possibility of unexpected circumstances that can lead to increased expenditures. As often mentioned often during the interview, these families had no savings, their budget was compensated in terms of revenue and expenditure. Extremely important was the notion that in difficulties, they can count on the immediate family. However, it is a stressful situation, the life in continuous lack of confidence, the risk of instability in life.

Only a few families in this study showed the difficulty in the current financial liquidity, which often results in sharing resources due to satisfaction of the most important needs of the family. No car, colour TV, washing machine is conditioned by several factors. In our system of support, there are many forms of assistance, e.g. PEFRON (State Fund for the Rehabilitation of the Disabled Persons) has organised several projects (including projects submitted to programme 2 “to increase the independence of people with disabilities”).

However, as noted, the lack of a washing machine and TV presented by respondents are connected with the possibilities of the use of these devices within a household, when subjects lived with their family (grandparents) in one house. Availability of telephone networks in terms of both price and capabilities of their use is further conditioned by the necessity to secure assistance in urgent situations, related to the care of people with disabilities.

### **Finances of Families with a Child with Autism**

An important element of the functioning of families with a child with autism are financial means that are earned to secure their livelihood. Work in the family (N = 43): father works 37 (86%), mother works 18 (42%), sibling works 4 (9%) and nobody works 4 (9%).

The vast majority of parents of children with autism worked. First of all, working fathers, which indicates a traditional division of labour - traditional family.

Substantial changes in the structure of the family are occurring in recent years. In previous studies, only fathers worked, whereas mothers cared for a disabled child and home. Currently, this structure is changing. Mothers are increasingly taking up paid work. We observe situations that parents take up professional work, and employ a babysitter to care for their child. In 2 cases, life situation forced the fathers who lost their jobs to take care of children and perform household duties. In four cases, the family already had children of legal age, which implemented their own life plans. Moreover, in 4 cases, families faced unemployment (2 cases of single mothers caring for the child and 2 cases where both parents became unemployed).

Changes in the structure and division of responsibilities are situations influenced by the economic situation of families, as well as economic and political situation of the country. Ongoing changes also force the transformation of family environment. In addition to obtained incomes, these families often had additional financial support: Social welfare centre 18 (42%); kindergarten 4 (9%); other institutions and people 10 (23%) and not benefiting from assistance 18 (42%). Families obtained assistance within social welfare (18), as well as in different institutions and people – most frequently the family (10).

Respondents did not indicate the use of the aid charities, including churches. Frequently, charities support those families non-financially – in the form of organisation of additional forms of therapy etc. Respondents were asked, from whom they would expect support - Who is expected by the family to help them: nobody - 19 (44%); family 3 (7%); the



state 22 (51%) and the church 2 (5%)

Most parents felt that the state should be more caring for families with children with autism. It was explained that the state should more efficiently use collected taxes. Some parents pointed to the family (7) and churches (2) as a possible supportive group. Nineteen families felt that they are capable of a full care and support of children with autism and its siblings. Frequently, these respondents showed fatigue during the search for support and determinism in looking for the most effective activity for their child. They often referred to this approach as “taking matters into their own hands”.

Respondents provided information about their disposable income per family member. Although not all families indicated the average income per family member, the largest group (18 persons, 44%) reported an average of more than 800 zł per family member. According to the Central Statistical Office, the average wage net in 2013 was about 2735 zł per month, which in the case of 4-member family gives an average of 680 zł per person. However, in the case of families with children with autism, additional care and support therapy are required, which involves additional expenditures (for fees related to the costs of commuting etc).

## SUMMARY AND CONCLUSIONS

Departing from clinical paradigm for the benefit of placing disabled people in the society provokes numerous reflections. They include the test results presented above. It is an attempt to draw attention to the quality of life, or, in fact, the level of deprivation of needs for the disabled.

Social rights are one of the three foundations of civil rights. Their aim is to equalize and mitigate the inequality of living conditions. We were interested to what degree children with autism and their families met the needs of the existence and development, and thus, lived to the fullness of citizenship. The more that the quality of life – e.g. participation in extra-curricular activities - in this case also served as a therapeutic factor.

It must be stressed again that this study is not representative, but only a contribution. A small population (less than 50 persons) was examined. Their selection was dictated by the ability of researchers, but it also derives from the fact that children with autism are a small group among the total number of disabled children. Similarly, a small percentage of children have certified autism.

Generally, the researchers were interested in the level of meeting existential and developmental needs. Traditionally, existential needs are related to nutrition, clothing and shelter. We were able to determine the level of the first two. It can be said that the surveyed children were not hungry. Not only did they eat cooked meals, but they frequently (every 5<sup>th</sup>) had sandwiches, which, according to the researchers, shows concern of parents and guardians. In contrast, the quality of food may raise anxiety. At least one third of them were not properly balanced meals. The lack of protein and fruit is an indicator of poor nutrition. (Such a situation is characteristic for the diet of all children (and adults) in Poland). It is not yet known to what degree this situation is caused by poor financial condition of the family - it requires further attention of researchers. 42% of respondents admitted to benefitting from social welfare and one third of the families had incomes on the verge of or below the statutory poverty, while another part (27%) had the double of it, which was still low amount of money.

In addition to the food, an important need is clothing, but it can also be said that is an element of participation in culture. Poor quality clothes do not meet their primary function, but are also a part of stigmatizing. Respondents wore -

almost all – appropriate and good quality apparel. Therefore, it can be judged that they were not excluded for that reason.

Developmental needs were analysed at the level of participation in the leisure time and education. While the majority of respondents (80%) had access to toys or games, and also had the opportunity to invite friends for various events (at similar levels), the problem became, satisfied at a much lower level than earlier, the needs of a joint holiday for the whole family and additional recreational activities. Common vacation was out of reach for half of the families, and developing additional activities are achievable for every third pupil (35%). The latter restriction may be largely influenced by place of residence (rural, small town) for a substantial part of the respondents.

To sum up: the deprivation needs of young children with disabilities caused by autism is a difficult issue. A substantial number of families benefiting from social welfare and low-income families should be alarming. The proportion is much higher than among the total number of children in Poland. However, families try to meet the basic needs of their disabled children. Exceptions are those needs, which are generally poorly satisfied in terms of the average Polish citizen, i.e.: properly balanced meals, eating fruit and access for additional classes and family vacation.

Even a study of a small group of children with such a specific type of dysfunction like autism can suggest some changes at the macro and micro level of social policy, or actions undertaken by various sectors of the society. Contemporarily, disability is perceived as one of the important factors of exclusion. Reduction of developmental or existential needs permanently excludes not only today, but it denies any chance for tomorrow.

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