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Financial support dedicated to families with autistic children in Poland

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Abstract

Effective treatment, therapy and rehabilitation in autism generate the different kind of high costs and require the multidimensional support, including financial support. In Poland there are different forms of financial assistance offered by different entities under the big number of legal regulations. In case of children suffering from the autism the financial support is offered both to children with autism, as well as their families. The article in part refers to financial support, presents the most important legal regulations, which are legal base for particular forms of financial assistance, as well as describes the main forms, range and amount of financial support to children with autism and their families.

Introduction

In the recent years, we are observing a development of specialised knowledge and a growth of the society's interest in the subject of autism. The situation of parents of children with autism is especially difficult. It results from numerous specific problems. They include large stress and fear of the child's future, education, work, future life, as well as issues related to the financial situation of such families. A lack of possibilities to communicate with a child and to develop proper bonds between a child and other family members, inharmonious and unpredictable development, when periods of improvement interchange with stagnation and regress are factors which increase the stress of parents.

Each family can experience difficult situations due to transformations and events that occur along with further stages of life (death, birth, divorce, foreign trip of a loved one). However, disability and illness of a family member is regarded as particularly burdensome (De Barbaro 1999). If we perceive a family in a systematic way, one should remember that effects of the occurrence of such disorder in one of its members concern not only the person but also

other people and the family regarded as a whole. In such a case, everyday life becomes a significant challenge, undertaken by the family, especially child's parents (Pisula 2012).

The issues related to burnout of strength of parents of children with autism were the subject of studies by E. Pisula (1998). The analysis concerned the importance of various factors (such as: sex of parents, level of their education, professional activity, family and financial situation, type of disability of a child – the author studied parents of children with autism, sex of a child, number of children in a family) for perception of own life situation and the level of parent's fear. The research showed that the level of fear is higher in the group of children with disabilities than in the group of able-bodied children.

According to studies of M. Sekułowicz (2013), a key factor for the functioning of a child with autism is the level of life satisfaction of parents.

Taking care of a child with autism is a challenge for the whole family. Without any doubt, in order to handle numerous burdens, parents need social and financial support for themselves and their children. High costs connected with rehabilitation and additionally stabilisation is not provided by social support, not being commensurate with needs.

Caring for a person with autism requires greater financial expenditures than in the case of other disabilities. Acquiring additional funds is a constant problem, thus, in the later stage of life, people with autism who live in social welfare centres are “expelled” from them.

Nowadays, none of the forms of Polish institutional support for people with autism plays its role properly. We can observe phenomena of multi-plane exclusion of persons with autism, concerning:

- double exclusion: from the society of able-bodied people due to the disability, and from the society of disabled people due to autism;
- financial exclusion due to a lack of systematic solutions and a mechanic use, in projects for disabled people, the criteria of results, of geographic and economical situation and due to a lack of availability of financing from national, self-government and EU funds.

As a result, it is essential to eliminate discrimination of persons with autism, in cooperation with the following entities: bodies of governmental, self-governmental authorities and non-governmental organisations.

There is a lack of daily, whole-day of temporal and constant stay facilities adjusted to the needs of people with autism.

People suffering from autism are disabled for their whole lives and need:

- education and specialised health care for the is whole life,

- support in a family within the scope of Special Care Services, short-term stay centres,
- social and professional activation,
- supported employment,
- specialised centres of constant stay.

The support subject in such approach includes mainly family, which needs financial support, which is first to set the direction of life and has the greatest influence on the development and future life of people with autism (Jankowska et al. 2014).

This is why the situation of and possibilities of financing families raising children with autism is very important.

Observed in the literature is a growing interest in chronic disease and disability in the context of costs it generates and funding of these costs.

Costs and financing of life, treatment and rehabilitation in Autism Spectrum Disorder of children

Autism is usually associated with substantial lifetime costs to an individual, their family, as well as the community and therefore it can be an expensive disorder. There may be specified the direct and indirect costs for the family with children suffering from autism. Under direct costs may be specified:

- Medical costs, which include the pocket of costs required for health services, diagnosis, therapies, medication. Diagnosis and therapeutic intervention are usually a lengthy and labor intensive process, and health services and medication are very costly.
- Support costs, which refer to daily activities, disability-specific aid, special equipment, travel, child care, specialist sport lessons or other activities, etc.
- School costs, which mainly refer special needs of disable children and necessity of special educational tools and specialist staff.

Under indirect costs of ASD may be specified:

- Loss of income from parents employment due to necessity of childcare (Członkowska, and Mirowska-Guzel 2005; Sowa and Włodarczyk 2017; Mitra et al. 2017).
- A delay in diagnosis or missed diagnosis, which generate large costs in the future. Accurate and timely medical diagnosis is necessary for optimal medical care (also in the point of view of financing the treatment).

Autism is associated with many serious impairments that have life-time consequences for families and great impact on household finance. A large economic burden is associated with caring for a child with ASD and they are

financed in most degree by the families of children and by the educational system, as well as by community and by government. They include the care cost (healthcare and support costs) and costs of special education services in public schools. These type of costs is very difficult to recognize (Członkowska and Mirowska-Guzel 2005; Lavelle et al. 2014).

Children with autism are often in the group of children with special educational needs (SEN). In previous years in many European Countries (including Poland) access to inclusive education was highly limited and most children with intellectual disabilities received education in a segregated environment and were not able to attend a mainstream school (Drabble 2013). Then the situation was changed. Today in European Union there is a general trend towards placement of children with SEN in mainstream education (inclusive education), and away from special schooling. Under the inclusive education there are support mechanisms available to parents of children with SEN, but the information about it is incomplete.

Large part of the costs of ASD is the loss of income from parents employment and each additional symptom costs the family additional sum of money (Prokopiak 2014; Horlin et al. 2014). It is very difficult to encompass the impact of a child's diagnosis on parent employment and estimate this category of costs (e.g., the cost of time taken out from current employment for treatment visits or reduced employment and income of parents due to childcare).

In addition parents of children with autism experience high level of stress, which also may generate additional costs, and a delay in diagnosis is usually associated with an indirect increased financial burden to families. The delay in the diagnosis may be associated with increase (at the modest level) in the number of ASD symptoms, indirectly impacting the cost of ASD. Like in many different disease types under the total cost of autism there also is the cost of not obtaining a diagnosis. In turn, an early diagnosis of autism which leads to early intervention may reduce the cost of ASD. Most beneficial effects are usually accomplished when intervention is commenced very early, between the ages of 2 and 4 (Harris, Handleman 2000).

Costs vary according to the severity of disability, life cycle and household composition and the highest costs are observed among persons (children) with severe disabilities (and in the case of adults among persons with disabilities living alone or in small sized households).

The necessity of additional outlay in the case of families with the presence of a household member (child) with disability has important implications for the financial situation of a household, including poverty (Orłowska and Błeszyński 2014). It is also recognized as a negative influence of the child's

disease, on health-related quality of life (HRQOL) of parents, which has also the implications for financial situation of family (household) (Ślifirczyk et al. 2016). The quality of life in families raising children with an autism spectrum disorder is getting worse. To achieve a reasonable standard of living, there are necessary different types of supports/assistance, including financial support. In many countries such families can get financial support from national, state, territory and local governments for children and teenagers with ASD. But social security system and other forms of supports vary in particular countries and family benefits differ greatly across the world.

Financial support for children with Autism Spectrum Disorder in Poland and its legal framework

Financial, as well as other types of social assistance for family with autistic children requires special legal framework. Poland has ratified most international human rights instruments, which enable the commissioning of appropriate support. Among them are provisions relating to the rights of people with disabilities, including children with autism. National legal framework in the area of support for family with autistic children covers (among others):

- Polish Constitution (Dz.U.1997.78.483) – which ensures special health care to children and persons with disabilities (Article 68), provides assistance to persons with disabilities to ensure their subsistence, facilitates their adaptation to work and social communication (Article 69) and guarantees the children’s rights (Article 72).
- Act on the Ombudsman for Children’s Rights (Dz.U.2000.6.69) – under this act the Ombudsman provides special care and assistance to children with disabilities (Article 3) and underlines that family is the natural environment for the child to develop (Article 1).
- Act on the Education System (Dz.U.2004.256.2572) – which (together with executive regulations) provides the children with disabilities development and education at each stage of life (Article 71b) and in all types of schools, taking into account their individual developmental and educational needs and predispositions (intellectual and physical), individual educational period, appropriate educational contents and forms, including special forms of teaching and personalised learning process and assessment of their knowledge as well as rehabilitation activities (Article 1–5), as well as free accommodation in a special educational-pedagogical centre, free transport and assistance to school or special centre (Articles 14a and 17).

- Charter of Rights for Persons with Disabilities (M.P.1997.50.475) – which guarantees the active life, without any discrimination, as well as the right to a barrier-free environment, including access to public buildings, transport, information and means of communication; the right to education; the right to work in the open labour market in adapted conditions; the right to participation in public, social, cultural life, etc.
- The Act on Vocational and Social Rehabilitation and Employment of Persons with disabilities (Dz.U.2011.127.721) – which among others together with executive regulations regulates disability assessment procedures (e.g. in case of children disability statement).
- The Act on Family Benefits (Dz.U.2003.228.2255) regulates the eligibility criteria for the entitlement to family benefits and the rules governing the award and payment of these benefits.
- The Act on Social Assistance (Dz.U.2009.175.1362) regulates the social assistance services and benefits eligibility criteria. It provides both financial benefits and non-monetary services.
- The Act on Social Pension (Dz.U.2003 135.1268) regulates benefits eligibility criteria for financial support from the Social Insurance Institution in case of being completely incapable of working.

Presented acts (and many others) are complemented by relevant executive regulations, communal resolutions, community resolution and other regulations (e.g. local governments).

Under presented national legal framework there are a range of benefits available to families with autistic children. The use of most of them requires the disability certificate to autistic children. Families, which have such disability certificates may apply for some benefits, including financial support. Support for children with disabilities in Poland is realized mainly through the family benefits and allowances system (under the Act on Family Benefits), as well as under the social assistance system (under the Act on Social Assistance).

The various categories of financial benefits depend on different terms, e.g. family income or child age and some of them is the same for each case. For example, the amount of family allowance depends on income and the child's age, and nursing allowance and nursing benefit do not depend on income of family and age of children. But it should be underlined that not all benefits and allowances are means-tested or depend on the age of children.

The most important benefits and allowances for disabled children and their families include:

A. Benefits for disabled children

Nursing Benefit – is granted to a handicapped child over 16 years of age who possess a medical certificate confirming severe disability and to a person older than 16 years of age with a medical certificate of moderate degree of disability if the disability occurred before the person reached the age of 21. The benefit is not granted to a person who is staying at an institution providing full time care if the services provided by the institution are financed by the state or the National Health Fund. The amount of nursing benefit is PLN 153 (The Act of November 28, 2003 – Journal of Laws of 2017, item 1428).

Social Pension may be granted to a child with a disability age a 18 or older. She/he can apply to the Social Insurance Institution for this kind of pension due to being completely incapable of working due to an impairment of bodily functions which occurred before the age of 18, or before the age of 25, if she/he was still in education process, e.g. university or other graduate and post-graduate studies. The amount of social pension in 2017 was PLN 840 and from 1 March 2018 it is changed to 865.03 PLN (The Act of June 28, 2003 (Journal of Laws of 2013, item 982 with changes).

B. Benefits supported families with disabled children

Nursing Allowance (*świadczenie pielęgnacyjne*): a benefit granted to a parent, a factual or statutory guardian, who resigns from employment or other paid job in order to take care of a child possessing a certificate confirming his/her disability. It used to be a means tested benefit but since January 1, 2010 it has become a universal benefit. Since 2013 the eligibility criteria for nursing allowance are limited to parents of those children whose disability occurred before turning 18 (or 25 in the case of children who continued their education after turning 18). The amount of nursing allowance was PLN 1406 in 2017 (PLN 1300 in 2016 and it is PLN 1477 in 2018).

Childcare Allowance (Family 500+ benefit) – is a benefit which is intended to give financial support in child rearing for families with children aged less than 18 years old. It is a universal payment of 500 PLN per month for every second child and any subsequent children. In the families with income below PLN 800 net per person (which excludes family benefits, housing support and social assistance benefits), support is also available to the first or only child. For families with a disability child, the income criterion is higher and amounts to PLN 1200 net.

Family allowance (benefit) is payable if the family income per person or the net income of a person studying does not exceed PLN 674 monthly or PLN 764 in the case where a member of the family is a disabled child.

Family allowance is payable per child and depends on child age:

- has reached 18 years of age; or
- has completed school education, however no longer than until s/he has reached the age of 21; or
- 24 years, if s/he continues education in a school or an institution of tertiary education and holds a certificate of moderate or severe degree of disability.

Table 1. The amounts of family allowance depend on the age group of the child

	From November 1, 2015 to October 31, 2016	From November 1, 2016 to October 31, 2017	From November 1, 2017
for a child until she/he reaches 5 years of age	89 PLN	95 PLN	95 PLN
for a child above 5 years of age until she/he has reached 18 years of age	118 PLN	124 PLN	124 PLN
for a child above 18 years of age until she/he has reached 24 years of age	129 PLN	135 PLN	135 PLN

Source: Regulation of the Council of Ministers of August 7, 2015 (Journal of Laws of 2015, item 1238); The Act of July 7, 2017 (Journal of Laws of 2017, item 1428)

Family allowance may be supplemented by various additional payments like: the supplement for the birth of a child, the supplement in respect of the care of the child within the period of parental leave, the supplement for a single parent bringing up a child, the supplement in respect of bringing up a child in a large family, the supplement for a child starting education in a school outside the place of residence or the supplement for a child starting the school year. All listed supplements may be benefit for each family meet the criteria but the families of disabled children may also benefit the supplement in respect of the education and rehabilitation of a disabled child (Regulation of the Council of Ministers of August 7, 2015 – Journal of Laws of 2015, item 1238; The Act of July 7, 2017 – Journal of Laws of 2017, item 1428).

In addition to listed allowance and benefits the disabled children and their families are entitled to benefits in transport and their parents may park at the special places reserved for disabled people, which are marked with a wheelchair symbol (Regulation of Minister of Labour and Social Policy of June 30, 2014 (Journal of Laws of 2014, item 870).

C. Other benefits

There is also possible the financial support from State Fund for Rehabilitation of Disabled People (PFRON) for professional activation and social rehabilitation of disabled persons and for children and youth. The Fund supports financially through additional financing for the purchase of domestic appliances necessary in daily life and rehabilitation and for subsidized rehabilitation camps, co-financing disabled students in education and in widely understood rehabilitation and social integration (rewarding the best master degree and PhD degree theses in general national competition, co-financing for sports, culture and recreation. Parents of disabled children also can apply to the National Health Fund (NHF) for orthopaedic and assistive devices. NHF reimburses expenses up to a certain amount. Additional financing is possible, under certain conditions, from the State Fund for Rehabilitation of Persons with disabilities. In addition, families with disabled children may also benefit from taxes benefits, e.g. rehabilitation tax credit. There are also special rights (resulting in financial support) of disabled children related to inclusive education.

Final remarks

In spite of various forms of financial support of children with autism and their families in Poland, this kind of assistance seems to be inadequate. Taking into account the costs of life of disabled children, the range and amount of financial supports do not cover very costly medical and non-medical expenses. The next problem is that the parents of children with autism are focused on rehabilitation and treatments of their children and not on the financial matters, in meaning of financial management during the treatment process. It is a great problem of most people, that they cannot manage their money. The lack or deficit of skills in financial management resulting in financial exclusion is wider problem of many fragile populations and vulnerable groups in the World (World Bank 2012; World Bank 2015).

And in the case of people with chronic disease, the problem of financial management is more complex. Parents and guardians of autistic children require greater knowledge on possibilities of financial and other (e.g. informative and institutional) forms of supports and skills on financial management under the treatment and rehabilitation processes.

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