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Autism as a Disability (from the Lawyer’s Perspective)

Abstract: Autism is a complex neurological disorder, one of the most important developmental disorders. The life and functioning of a person with the autism spectrum is very complex and difficult, and the psychological burden of the whole family is very high. The clinical picture is very complicated and its origins are unknown. People with autism differ from each other in both the level of intelligence and the extent of the disorder. Scientific research has proven that despite the similarities among people with autism spectrum there are huge differences between these people. Autism as a pervasive development disorder was introduced in Polish law on 01/01/2010 – marked with the symbol 12-C. Disability in Polish law does not have one universally applicable definition. The large number and variety of legal acts concerning people with disabilities causes information chaos, making it difficult to identify instruments for the effective enforcement of such rights. Autism as a pervasive developmental disorder disturbing the functioning of the whole organism to a large extent, is a severe disability. Specialists diagnosing the disease in most cases include it in the deepest, i.e. significant degree of disability.

Keywords: autism, autism spectrum disorder, discrimination, disability, holistic development disorder, statute, charter of disabled people rights, EU, WHO, developmental disorders.

The term “autism” is derived from the Greek word “*autos*” meaning “alone”. It was used for the first time by a Swiss psychiatrist Eugen Bleuler, who in 1911 described schizophrenia as a disease entity including the closure in their own world and relaxing the discipline of logical thinking among its axial symptoms. However, this was not the first case of describing children closeted in “their own world”. In old fairy tales, myths and legends, information about children developing properly, but later

being changed or taken away by a fairy can be found. In folk predictions, there have been examples of children not interacting with people and not afraid of any dangers¹.

Despite the 75-year history of scientific struggles, autism is a disorder that implies a number of doubts and questions, prompting to continually search for undisclosed answers. The complexity of issues experienced by people with autism spectrum disorder and their family members motivate many specialists: researchers and practitioners to help improve the quality of life of these people and their families. Currently, science provides knowledge on the causes of the disorder and its mechanisms, as well as on the treatment methods, whereas care and hope allow us to change the reality of people with autism spectrum disorder, creating conditions for a life with dignity.

For many years, the understanding and social approach to the disabled person and their place in society have changed – from exclusion, stigma, through tolerance, acceptance and inclusion. Broadly understood equality, emancipation is the pursuit of social equality according to the needs and abilities of each person. It should be emphasized that it is also an idea of recognizing the rights of people who are excluded due to their otherness, differences in behavior, possibilities of functioning and performing various social roles.

1. What is autism?

In 1994, autism was classified as pervasive developmental disorders category (12-C). Every person with this disorder differs individually; therefore the location of autism among other diseases was subject to constant change. By contrast, in 2010, the 12-C code was introduced in Polish jurisprudence. Until now, people with autism have been obtaining the code indicating a disability e.g. due to neurological defects or mental illness. The introduction of the code will help to estimate the number of births of people with autism in Poland, but it can only happen in a few years². The continuous lack of computerization of the disability certification system is another obstacle, which prevents the creation of nationwide databases allowing for realistic measuring of the number of certificates mentioning autism and for creating lists, for example, for individual regions³.

1 L. Bobkowicz-Lewartowska, *Autyzm dziecięcy-zagadnienia diagnozy i terapii*, Kraków 2011, p. 11.

2 It applies to the earliest possible diagnosis of a child. It is now possible to diagnose a child at the age of 16-30 months, which accelerates the effective rehabilitation of those with autism spectrum disorders.

3 Data on autism, the Fundacja Synapsis website: <http://www.synapsis.org.pl/autyzm/skala> (access 4.10.2018).

It should be remembered that comorbidities occur in more than 75% of people with ASD (Autism Spectrum Disorder) and are one of the most important aspects of the diagnosis. However, the diagnosis of ASD is not a complete picture. Autism spectrum often occurs with intellectual disability, ADHD, oppositional defiant disorder (ODD), anxiety disorders, depression, tics, etc. and other disorders such as gastrointestinal ones or sleep related. In contrast, in adults bipolar disorder and schizophrenia coexist⁴.

It should be emphasized that early diagnosis of a child with autism should be the first step in therapy, rehabilitation, education and in adult life. The Synapsis Foundation has launched a nationwide screening program for autism. The Polish version of the diagnosis tool for children between the ages of 16 and 30 months⁵. The duration of the "Badabada" Early Autism Detection Program was planned for a period of 5 years. Its aim is to introduce and disseminate procedures, standards and tools that allow to monitor the child's development in the first years of life, to capture symptoms from the autism spectrum (ASD) or ASD risk at the stage of their manifestation. The Synapsis Foundation expects the Program to reduce the degree of disability caused by ASD disorders through rapid intervention in the early stages of disorders, and therefore wants to aim for a possibly large group of children (at least half the population above 1 year of age) to be screened as part of routine care activities (nurseries, pediatric clinics, POZ). After performing both diagnostic activities, parents will receive written information about the degree of ASD risk or determine the child's atypical behavior and the further steps they should take. The program is to be piloted in selected institutions, and ultimately all over in Poland.

The diagnosis of autism in a child affects each family in a different way. Parents must focus on helping the child with autism spectrum, and devote less attention to the issues of marriage, other children, work, finances or personal relationships and responsibilities. These families may face many challenges and stress factors that affect their children's development, cohesion and quality of life. Important factors that affect families are the availability of an appropriate support and advisory system, as well as cooperation with professionals focused on developing common goals. It should be noted that people professionally involved in this issue participate in the training of

4 M. Fitzgerald (Department of Psychiatry, Holy Trinity College in Dublin, at the International Scientific Conference, Focus on Autism, Kraków 2018, p. 41) emphasizes that people with ASD: are commonly prescribed with drugs such as: Ritalin, Risperidone, Melatonin and antidepressants - especially in connection with the progressive age of the patient. Sometimes, instead of the diagnosis of ASD, there is a diagnosis of a coexisting disorder, which has serious consequences for treatment and quality of life. The range of these comorbidities may vary depending on the problem: with ADHD 25-50%; epilepsy 7-30%; sleep disorder 80%; intellectual disability 54%; obsessive-compulsive disorder 8-37%; anxiety disorder 10-60%; tics 11-22%; depression 1-50%; oppositional and rebellious disorders 27-40%.

5 Early detection of autism can be found on the website <http://www.badabada.pl> (access 21.11.2018).

people with autism spectrum, while parents generally do not use training or get little support in this regard⁶. It should be emphasized that non-governmental organizations operating throughout the country attempt to help parents by implementing all types of projects related to people with autism spectrum, *de facto* these are only consultancy measures and not long-term activities.

The dominant feature in the behavior of children with autism spectrum is the impaired ability to perceive, understand and respond appropriately to desires and intentions of others. These difficulties in social interactions or in communication help to see the issue of autism spectrum. Currently, the most attention is devoted to eye contact and face-to-face interaction, imitation skills, pretend playing, sharing attention or intentional communication. *De facto*, the earliest diagnosis of autism contributes to the start of therapy, which significantly alleviates its effects.

Autism is noise and chaos. A disorder that cannot be arranged. This is how one patient describes his condition in a book authored by Katarzyna Markiewicz⁷, that results from many years of research, therapeutic and diagnostic practice. It should be emphasized that there are many more valuable publications available which concern the feelings, experiences and attempts to understand people with autism spectrum⁸.

Autism is characterized by significant quantitative and qualitative disorders in communication, in the social sphere and in behavior. There is a group of autistic people who do not communicate verbally. Due to the depth of their autistic disorder, verbal language has not developed. Most often, such people are assessed as low-functioning, often they are relieved of school duty. This group of autistic people included Maciej Oksztulski – the co-author of this paper⁹.

6 Facing a son's autism. The mother of the co-author has been working in non-governmental organizations in the city of Białystok for over twenty years, first with the National Autism Society Department [Oddział Krajowego Towarzystwa Autyzmu] and then with the "Oswoić Świat" Foundation, of which she is a co-founder and board member.

7 K. Markiewicz, *Charakterystyka zmian w rozwoju umysłowym dzieci autystycznych*, Lublin 2007, p. 69. The author reviews theories and views on the issues of autism and presents the effects of her own research on changes in mental development with autistic children. A valuable part of the work is the description of individual case studies. The book also indicates guidelines for improving the development of autistic children or the characteristics of changes in their mental development.

8 E.g. . Shore, *Za ścianą. Osobiste doświadczenia z autyzmem i zespołem Aspergera*. Warszawa 2008.; J. Copeland, *Z miłości do Ani*, Warszawa 1995.; D. Zoller, *Gdybym mógł z wami rozmawiać...* . Warszawa 1994.; R. Kawa, *Wypalenie zawodowe a jakość życia terapeutów pracujących indywidualnie z osobami z autyzmem. Dziecko Autystyczne*, Warszawa 2010, vol. XVIII no. ½, pp. 119 – 125.

9 He is the only autistic not speaking person in Poland, who (in 2015) obtained a master's degree in law at the Faculty of Law at the University of Białystok, full-time studies. In 2017 he completed a research internship in the United States at Syracuse University College of Law, during which he obtained the necessary data to analyze the American legal standard in the education of people with autism.

Autism is more and more often referred to as a civilization disease, as the number of people affected by it increases from year to year. The national data are still changing, but it is estimated that the number of autistic people is in its tens of thousands, although there is no data on the distinction between the number of children and the number of adults. In the near future, autism, along with cancer, AIDS and diabetes will be one of the most serious problems affecting human health. The clinical picture of autism spectrum is very complex and the reasons for its formation are essentially unknown. On the one hand, people with autism differ with respect to the level of intelligence, on the other hand – to the extent and depth of the disorder. Scientific research has proven that, despite the presence of similarities in autistic people, there are huge differences between them¹⁰.

Currently, people affected by autism can benefit from learning in special, integrational and public schools. They are attended not only by higher-functioning children, but also by people causing more educational problems. Pursuant to the Act of 7 September 1991 on the education system: *A child with autism or pervasive developmental disorders may fulfill the school obligation in a public school, an integration school, an integration ward, a special school in a special ward and other alternative forms permitted by Polish law*. It all depends on how soon after the diagnosis the decision about early treatment and education will be made. On the one hand – thanks to this in the future, the child will find a place in the school world faster, but on the other hand – intensive work with them should be introduced from the moment he/she is diagnosed to the time he/she goes to school. Naturally, everything is based on the opinion on need for early support of the child's development or on the basis of the decision on need for special education, if the child starts learning in a pre-school group¹¹. According to the above-mentioned act, people with autism find their place in pre-school and school education as due to the high cost of education they benefit from the conversion factor of 9.5, which is the highest in the disability scale, due to the special nature of the disability. Thus, there is a significant improvement in the education of children with autism. It should be noted that the autistic child of pre-school age is not able to make contact with their peers, they isolate themselves. They are hyperactive, they follow their own patterns, and any reaction of the environment can trigger aggression. The autistic child has great difficulty communicating, cannot play with their peers, they are not attractive to them. They are also unattractive to their peers. They often get angry, aggression and auto-aggression occur. During the school period there are still communication disorders, behavioral difficulties and other behaviors "stereotypical" for individual units¹². Many autistic children of this age reveal their talent in some field, for example: mathematics, art, music, or learning

10 J. Bluestone, *Materia autyzmu. Łączenie wątków w spójną teorię*, Warszawa 2012, p. 1.

11 Rozporządzenie z dnia 4 kwietnia 2005 r., „Monitor Polski”, No. 68, item 587.

12 L. Bobkowicz-Lenartowska, *Autyzm dziecięcy... op. cit.*, pp. 18 - 19, 23, 51 - 57, 64 - 67.

foreign languages. Unfortunately, the ability to think abstractly, understand the context of conversation, or intonation is disturbed. The big problem is the lack of contact with peers. They are often misunderstood, ridiculed, unable to communicate with them¹³. They go “in their own ways”, often trying to get close contact with teachers. They do not perceive their differences. They are disturbed by the noise at school, constant changes. Much depends on the conditions that the school can provide. According to Gałka and Pęczkowska¹⁴, emphasis should be placed on: getting a wide knowledge on autism, organizing the school environment, elimination of excess sensory stimuli, cooperation with institutions, conducting a child’s therapy, creating an individual education program, revalidation classes and constant contact and cooperation with parents. It is from them that teachers get the most information about the child. If the autistic student graduates high school and passes the matriculation exam – there is a chance for them to take up studies.

Students from the autism spectrum may experience certain difficulties. Most often here are: difficulties in contact with other students and teachers, poor understanding of social code contained in body language and social symbolism (hence frequent maladjustment to the situation, perceived by the surrounding “otherness” in dealing with others, such as excessive seriousness, eccentricity, social naivety, childishness, ineptitude in performing typical social roles, etc.), feeling fear in social situations, especially during a conversation, inability to conduct dialogue and cooperation, one-sidedness of social behavior, e.g. a tendency to monologue, not to let others speak or, on the contrary, only to listen in silence, as well as the need to maintain a certain routine in their behavior, or resistance to change and dramatic experience of sudden unexpected changes, poor organizational skills, easy distractions, the need for a concrete and logical consequence in everything, literal understanding of phrases and texts, non-differentiation between relevant issues and non-essentials, or meticulousness, excessive focusing on details, excessive perfectionism, as well as low resistance to stress and triggering regressive behaviors in difficult situations¹⁵.

The counterweight to these difficulties are individual features that can help at studying, and sometimes even allow to gain an advantage over other students. In fact, these include the excellent memory capacities often found in this group, including the capacity and durability of memorized facts and structural elements. If they are motivated, they can quickly master new areas of knowledge, from different often

13 J. Błeszyński, *Rodzina jako środowisko osób z autyzmem*, Toruń 2005, pp. 100, 129 - 133.

14 U. Gałka, E. Pęczkowska, *Dziecko z autyzmem i Zespołem Aspergera w szkole i przedszkolu*, Centrum Metodyczne Pomocy Psychologiczno – Pedagogicznej, Warszawa 2009.

15 See more: R. Stefańska - Klark, *Zespół Aspergera – nienormalność, wysoce oryginalna odmienność czy po prostu ekstremalny wyraz w zakresie pewnych różnic indywidualnych?*, [in:] *Żyć wspólnie: odkrywać Innego, przeciwdziałać zniewoleniu, realizować wspólne cele*, Kraków 2005.

thematically distant areas, and attach them to that already possessed, which makes them “walking encyclopedias”. Although, at least at the beginning, this knowledge may not be easily analyzed or reflected, giving the impression of a mere ballast, the gradual mastering of mental methodologies makes these students admirable experts, sometimes interdisciplinary¹⁶. Their legal status is determined by legal standards of disability. The Ministry of Science and Higher Education emphasizes that “(...) the recipients of legislative actions are all people with autism spectrum disorders with a certified disability, who are not distinguished from the group of disabled people. Therefore, in the current legal state, the adjustment of the assistance to the needs of certain students with autism spectrum disorders remains within the autonomy of the university”¹⁷.

The Act on Vocational and Social Rehabilitation and Employment of People with Disabilities¹⁸ aims to compensate for the differences in chances on the labor market arising from disability. However, the employment rate of persons with autism remains at a very low level, and their income from work, even if supported by retirement or care benefits, often places these people in marginalized positions.

The mental barrier of the Polish society does not allow people with autism spectrum disorders to find their place in the labor market, despite the huge amounts of EU funds (e.g. in the Regional Operational Program of the Podlaskie Voivodship for 2014-2020 [*Regionalny Program Operacyjny Województwa Podlaskiego na lata 2014-2020*] within Axis VII *Improving social cohesion, Measure 7.1. Active development integration* [Oś VII *Poprawa spójności społecznej, Działanie 7.1. Rozwój aktywnej integracji*] are directed at professional activation, including job creation in social enterprises for the excluded and supporting social entrepreneurship (under Measure 7.3 *Strengthening the role of the social economy in socio-economic development of the Podlaskie Voivodship* [Działanie 7.3 *Wzmocnienie roli ekonomii społecznej w rozwoju społeczno-gospodarczym województwa podlaskiego*])¹⁹. The measures of the operational programs implementing the EU funds are *ad hoc*, and meaningfully they can be implemented usually by non-governmental organizations²⁰.

16 Studenci z autyzmem i Zespołem Aspergera, available online on: https://www.researchgate.net/publication/322021685_Studenci_z_autyzmem_i_zespolem_Aaspergera_Funkcjonowanie_przyczyny_sukcesow_i_porazek_warunki_skutecznego_wspierania (access 5.10.2018).

17 Response to the interpellation no. 1768 regarding the students and PhD students with autism, dated 29 March 2016, of the Secretary of State in the Ministry of Science and Higher Education Aleksander Bobko.

18 Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnieniu osób niepełnosprawnych (Dz. U. 2008, No. 123, item 776).

19 See more: Oksztulski M., Prawo do pracy osób z niepełnosprawnością – autyzmem w prawie i praktyce (na przykładzie województwa podlaskiego), MA thesis supervised by prof. Maciej Perkowski, Wydział Prawa Uniwersytetu w Białymstoku, Białystok 2015, pp. 85 – 87.

20 One such example is the Fundacja Wspólnota Nadziei, which in the period January 2010 - December 2011, implemented the European Social Fund project under the Human Capital

Counteracting social exclusion of people from marginalized groups is one of the important elements of our joint responsibility for social issues. The idea can be realized by employers' support in employing people with autism, it can bring tangible benefits (not only an image value) to the employer. The participation of a person with autism at work in any institution or company teaches all greater sensitivity and empathy, openness and attitude of kindness and acceptance for others; teaches how to draw experience, knowledge and ideas from diversity. It is a prerequisite for balanced social development, affects the personal development of colleagues and deepens understanding of interpersonal relationships, helps to get rid of many fears and frees people from thinking in terms of stereotypes about other people. Thanks to such experiences, social inclusion of people with disabilities, including the autism spectrum, has a chance to become a natural and real process.

2. Law and autism as a disability

People with reduced sensory or intellectual efficiency or reduced functional capacity are classified as people with disabilities. This category includes people with reduced communication, mobility, psychophysical skills or people with cerebral palsy. Autistic people are usually sensory, often intellectually disabled, with reduced social functionality and communication skills. Since 1996, the National Health Fund [*Narodowy Fundusz Zdrowia*] has used the classification of the World Health Organization (WHO), where autism, as a disease entity, has the symbols F84 (F84.0 to F84.9)²¹. It is worth pointing out that according to the WHO: *A disabled person is a person whose impairment and lowering in the body's functioning efficiency make social functioning impossible, difficult or limiting, taking into account such factors as gender, age and external factors*²².

In the European Union, the rights of persons with disabilities are defined differently in the various Member States. It should be emphasized that highly developed countries have legal provisions directly concerning autistic people, while countries with weaker economic condition are based on provisions referring in general to disability. On the other hand, the countries in which the aid was not sufficiently comprehensive and effective have introduced legal regulations which

Program - measure 7.2.1, project. Support for employment of adults with autism (the project covered 60 people from the autism spectrum from the Małopolska province).

21 Zał. Nr 6 do zarządzenia Nr 65/2007/DSOZ, Prezesa NFZ z dnia 20 września 2007 r. w sprawie określania warunków zawierania umów (Dz. U. No. 210, item 2135, with amendments).

22 The WHO definition of disability, available on: http://www.bon.edu.pl/budw/-menu_glowne (access 6.10.2018).

separately refer to the problems of people with autism – taking into account the specificity of disability caused by autism²³.

In European Union law: Council Directive 2000/78/EC of 27.11.2000 establishes a general framework for equal treatment in employment and occupation²⁴. It is implemented by the judgment of the Court of 11.07.2006 in the case of Sonia Chacón Navas against Eurest Colectividades SA²⁵, defining disability as a limitation, resulting specifically from a physical, mental or psychological dysfunction, constituting an obstacle for a person to participate in professional life. The Court also emphasizes that to fall within the concept of disability, it must be likely to be long-term. As a result, a person with whom an employer terminates a contract of employment solely because of illness is not covered by the general framework established by Directive 2000/78 to combat discrimination based on disability.

For the identification of the legal status of autism in the European Union, Art. 5 of the Council Directive 2000/78 of 27.11.2000 is important in providing rational accommodations for people with disabilities: *In order to guarantee compliance with the principle of equal treatment in relation to persons with disabilities, reasonable accommodation shall be provided. This means that employers shall take appropriate measures, where needed in a particular case, to enable a person with a disability to have access to, participate in, or advance in employment, or to undergo training, unless such measures would impose a disproportionate burden on the employer. This burden shall not be disproportionate when it is sufficiently remedied by measures existing within the framework of the disability policy of the Member State concerned.* It should be emphasized that the Charter of Fundamental Rights²⁶ in Art. 21, directly concerning people with disabilities, prohibits all kinds of discrimination. A similar provision, though more general, is in the Constitution of the Republic of Poland, in

23 For example: as part of the Think Autism Strategy in 2014, the UK government allocated £4.5m to the Innovation Fund for autism and the autistic-conscious community; <http://www.autism.org.uk/about/strategy/2010-strategy.aspx> (access on 14.10.2018), another example is Hungary, where the strategy on autism aims to improve the quality of life of people affected by autism at the stage of early selection, diagnosis, education, adult training, employment and family support (more on: F. Dell, R. Cera, Protecting the Rights of People with Autism in the Fields of Education and Employment, Springer Open). Denmark was one of the first countries in the world to open up the education system to people with disabilities, where people with autism spectrum have their place (A. Zawisłak, Organizacja kształcenia specjalnego w duńskiej szkole podstawowej, [in:] Z. Gajdzica (ed), *Rozwój i funkcjonowanie osób niepełnosprawnych. Konteksty edukacyjne i prawne*. Kraków 2007, p. 83.).

24 Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation. Official Journal L 303, 02/12/2000 P. 0016 – 0022.

25 Judgment regarding Directive 2000/78 / EC on equal treatment in the field of employment and work - Concept of disability, <http://www.curia.europa.eu/juris/showPdf.jsf?jessionid=9ea7d2dc> (access 14.10.2018).

26 E., *Dziecko z autyzmem i Zespołem Aspergera w szkole i przedszkolu*, Warszawa 2009.

Art. 32, par. 2: *No one shall be discriminated against in public, social or economic life for any reason*²⁷. However, Art. 26 of the Charter of Fundamental Rights states that: *The Union recognises and respects the right of persons with disabilities to benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community*. On the other hand, a very similar wording in Art. 69 of the Constitution of the Republic of Poland should be noted: *Public authorities shall provide, in accordance with statute, aid to disabled persons to ensure their subsistence, adaptation to work and social communication*. Also, Art. 32 para. 1 of the Constitution on equality of all citizens before the law should not be overlooked.

Determining the status of autism is not conducive due to the fact that there is no universally valid definition of disability in Polish law. In accordance with the Act on Vocational Rehabilitation and Employment of People with Disabilities: *Disabled persons are people whose physical, mental or mental condition permanently or periodically impedes, limits or prevents the performance of social roles, in particular resulting in inability to work*²⁸. In turn, in the resolution of the Sejm of the Republic of Poland of 1.08.1997 regarding the Charter of the Rights of Disabled Persons, the notion of disability is defined as follows: *persons whose physical, psychic or mental abilities permanently or periodically obstruct, limit or prevent daily life, studying, working and performing social roles in accordance with legal norms and customs*²⁹.

In practice, there are two separate certifying systems confirming the disability: on the degree of disability and on incapacity to work (also there are judgments on disability to work on a farm and regulations regarding uniformed services). The disability certification is governed by the provisions of the Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities of 27 August 1997. They are based on the medical disability model, with many defects, internally contradictory, using vague, also pejorative terms; the classification of disabled person to the appropriate degree cannot be done on its basis. In the above Act, Art. 2 describes disability as: *the permanent or periodic inability to fulfil social roles due to permanent or long-term violation of the body's efficiency, in particular resulting in inability to work*. Art. 3 sets three levels of disability: significant, moderate and light. Their definitions are included in paragraph 1-3 art. 4 i.e.:

- 1) *the significant degree of disability applies to the person with disturbed efficiency of the body, unable to work or capable of working only in the conditions of employment and requiring, in order to perform social roles, permanent or*

27 Konstytucja RP z dnia 2 kwietnia 1997 r., art. 32, ust. 2 (Dz. U. 1997 No. 78, item 483).

28 Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych (Dz. U. 2008 No. 123 item 776 with amendments).

29 Karta praw osób niepełnosprawnych, uchwała Sejmu Rzeczypospolitej Polskiej z dnia 1 sierpnia 1997 r., art. 1 (M.P. of 1997, No. 50, item 475).

long-term care and help of other people in connection with the inability to independent existence.

- 2) *the moderate degree of disability applies to the person with disturbed efficiency of the body, unable to work or capable to work only in sheltered employment conditions or requiring temporary or partial assistance of other persons to perform social roles.*
- 3) *the light degree of disability applies to the person with disturbed body efficiency, resulting in a significantly reduced ability to perform a job compared to the capacity of a person with similar qualifications with full efficiency and physical ability, or with restrictions in the exercise of social roles that are offset with the help of orthopaedic equipment, auxiliaries or technical measures.*

In the definition of the significant degree of disability, the legislator used the term *inability to independent existence*, explaining it as *the impairment of the body to the extent not enabling to satisfy the basic needs of life without help of other people, considering primarily self-service, mobility and communication.*

According to the Act on retirement pensions and other pensions from the Social Security Fund of 17 December 1998³⁰, an individual who has totally or partially lost the ability to perform paid work for health reasons and is unlikely to regain the ability to work after he has been retrained shall be deemed to be an individual unable to work:

- 1) *An individual who has lost the ability to perform any kind of work shall be deemed to be an individual totally unable to work.*
- 2) *An individual who has to a significant extent lost his ability to perform work in keeping with his qualifications shall be deemed to be an individual partly unable to work.*

The judgment on complete incapacity to work *de facto* does not mean a work ban, and many of people who have obtained the judgment do work. Often, the definition of total incapacity to work misleads employers who do not want to employ persons with such a judgment. Changes in this area require the amendment of the Constitution so that art. 67 of the Constitution of the Republic of Poland guarantees persons with an appropriate degree of disability the right to social security, which should be structured in such a way as to support the maximum use of the work potential of a given person. People with profound disabilities should have the highest social security.

The nature of these wordings is pejorative and at the same time imprecise. It should be emphasized that the purpose of social and professional rehabilitation

30 Ustawa z dnia 17 grudnia 1998 r. o emeryturach i rentach z Funduszu Ubezpieczeń Społecznych, (Dz. U. 1999, No. 162, item 1118).

is the ability of disabled people to fulfill social roles and being employed, so the legislator itself undermines the sense of the act. It should be noted that due to the development of new technologies, but also changes in the society's approach to the issue of disability, people with different types and degrees of disability now fulfill social roles that once seemed unachievable to them. According to the definition of the significant degree of disability, these people have impaired ability and are not able to function independently. The process of rehabilitation or the elimination of barriers in the environment also have an impact on the possibility of functioning in society.

It should be emphasized that the large number and diversity of legal acts concerning persons with disabilities increases public awareness in this respect, however, it causes a great deal of information chaos, in which it is difficult to identify instruments for the effective enforcement of such rights. For their real respect, it is essential to monitor the observance of these rights by both public entities and non-governmental organizations appointed for these purposes.

3. Conclusions

Pervasive developmental disorders are a group of neurodevelopmental dysfunctions significantly affecting the overall life of patients and their families. Recognized at an early age, in most cases they accompany patients suffering from them throughout their lives. They are also a significant burden for their relatives – one of the largest in psychiatry³¹. In fact, overall developmental disorders in one of the family members have a significant impact on the family life cycle and the course of its individual phases. It should be emphasized that each stage of measuring the diagnosis of overall developmental disorders confronts a clinician with different diagnostic and therapeutic challenges. Experts are expected to give advice related to specific decisions or life dilemmas. This applies to both the person with autism spectrum and the reactions of relatives to their illness; from the first suspicions of the presence of autism, through the process of reaching a diagnosis, intensive treatment, searching for miraculous therapies, reconciliation with the child's condition, their changing functioning during adolescence, adulthood challenges and finally fear of what will happen to a person with autism spectrum after the death of parents³².

It should be strongly stated that autism as a pervasive development disorder (12-C), which disturbs the functioning of the whole organism to a large extent, is a disability. Specialists diagnosing the disease in most cases include it in the deepest,

31 M. Pilecki, Całościowe zaburzenia rozwoju w biegu życia, Międzynarodowa Konferencja Naukowa: Focus on Autism, Kraków, September 2018, p. 99.

32 *Ibidem*.

i.e. significant, degree of disability³³. Only dignity as a special value of a human being as a person remaining in interpersonal relationships justifies and gives sense to a personal life and makes the attitude towards oneself and the group from which a given person originates positive. While early diagnosis, therapy, rehabilitation and education as well as finding a place in the labor market relieve symptoms of autism.

BIBLIOGRAPHY

- Bluestone J., *Materia autyzmu. Łączenie wątków w spójną teorię*, Warszawa 2012.
- Błężyński J., *Rodzina jako środowisko osób z autyzmem*, Toruń 2005.
- Bobkiewicz-Lewartowska L., *Autyzm dziecięcy-zagadnienia diagnozy i terapii*, Kraków 2011.
- Charter of Fundamental Rights of the European Union, 26 October 2012, 2012/C 326/02.
- Copeland J., *Z miłości do Ani*. Warszawa 1995.
- Data on autism, the Fundacja Synapsis website, available on: <http://www.synapsis.org.pl/autyzm/skala> (4.10.2018).
- Dell F., Cera R. *Protecting the Rights of People with Autism in the Fields of Education and Employment*, Springer Open.
- Directive 2000/78/EC of 27 November 2000 establishing a general framework for equal treatment in employment and occupation. Official Journal L 303 , 02/12/2000 P. 0016 – 0022.
- Fitzgerald M., *Międzynarodowa Konferencja Naukowa, Focus on Autism*, Kraków 2018.
- Gałka U., Pęczkowska E., *Dziecko z autyzmem i Zespołem Aspergera w szkole i przedszkolu*, Warszawa 2009.
- Judgment regarding Directive 2000/78 / EC - equal treatment in the field of employment and work – the concept of disability: <http://www.curia.europa.eu/juris/showPdf.jsf?jessionid=9ea7d2dc> (14.10.2018).
- Karta praw osób niepełnosprawnych, uchwała Sejmu Rzeczypospolitej Polskiej z dnia 1.08.1997 r., art. 1 (M.P. 1997, No 50, item 475).
- Kawa R., *Wypalenie zawodowe a jakość życia terapeutów pracujących indywidualnie z osobami z autyzmem. Dziecko Autystyczne*, Warszawa 2010, vol. XVIII no. ½.
- Konstytucja RP z dnia 2 kwietnia 1997 r., art. 32, ust. 2 (Dz.U. No. 78, item 483).
- Markiewicz K., *Charakterystyka zmian w rozwoju umysłowym dzieci autystycznych*, Lublin 2007.
- Odpowiedź na interpelację nr 1768 w sprawie studentów i doktorantów z autyzmem, z dnia 29 marca 2016 r., odpowiadający: sekretarz stanu w Ministerstwie Nauki i Szkolnictwa Wyższego Aleksander Bobko, [Response to the interpellation No. 1768 regarding the students and PhD

33 Currently, the discussions are underway on whether autism is a disease because there are no means of treatment (medication or surgical procedures), the problem has been raised at the International Scientific Conference, Focus on Autism, Krakow 2018 – the opinions were very divided.

- students with autism, dated 29 March, 2016, of the Secretary of State in the Ministry of Science and Higher Education Aleksander Bobko].
- Oksztulski M., Prawo do pracy osób z niepełnosprawnością – autyzmem w prawie i praktyce (na przykładzie województwa podlaskiego), MA thesis supervised by prof. Maciej Perkowski, Wydział Prawa Uniwersytetu w Białymstoku, Białystok 2015.
- Pilecki M., Całościowe zaburzenia rozwoju w biegu życia, Międzynarodowa Konferencja Naukowa: Focus on Autism, Kraków, September 2018.
- Rozporządzenie do ustawy o systemie oświaty z dnia 4.04.2005 r., MP, No 68, item 587.
- Shore S., Za ścianą. Osobiste doświadczenia z autyzmem i zespołem Aspergera. Warszawa 2008.
- Stefańska-Klark R., Zespół Aspergera – nienormalność, wysoce oryginalna odmienność czy po prostu ekstremalny wyraz w zakresie pewnych różnic indywidualnych?, [in:] *Życie wspólnie: odkrywać Innego, przeciwdziałać zniewoleniu, realizować wspólne cele*, Kraków 2005.
- Studenci z autyzmem i Zespołem Aspergera, dostęp intern. https://www.researchgate.net/publication/322021685_Studenci_z_autyzmem_i_zespołem_Aaspergera_Funkcjonowanie_przyczyny_sukcesow_i_porazek_warunki_skutecznego_wspierania (5.10.2018).
- Thing Autism Strategy, internet: <http://www.autism.org.uk/about/strategy/2010-strategy.aspx> (14.10.2018).
- Ustawa o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych z 27.08.1997 r. (Dz. U. 2008 No. 123 item 776 with amendments).
- Ustawa o emeryturach i rentach z Funduszu Ubezpieczeń Społecznych, 17.12.1998 (Dz.U. 1999, No. 162, item 1118).
- Załącznik Nr 6 do zarządzenia Nr 65/2007/DSOZ, Prezesa NFZ z dnia 20 września 2007 r. w sprawie określania warunków zawierania umów (Dz. U. No. 210, item 2135, with amendments).
- Zawiślak A., Organizacja kształcenia specjalnego w duńskiej szkole podstawowej, [in:] Z. Gajdzica (ed.), *Rozwój i funkcjonowanie osób niepełnosprawnych. Konteksty edukacyjne i prawne*. Kraków 2007.
- Zoller D., *Gdybym mógł z wami rozmawiać...*, Warszawa 1994.