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Non-employment of persons with autism spectrum disorders in the Polish legal and digital reality

The Convention on the Rights of Persons with Disabilities, adopted by the United Nations in 2006, provides all persons with disabilities with equality before the law and prohibits any discrimination. It also guarantees the right to work. The issue of employing persons with autism has been the subject of many scientific studies in the English-language literature while in the Polish science this area is still poorly researched or described. Individuals with this type of disorder constitute a challenge for the Polish education and employment in the open job market. The root of these problems lies in social prejudices and fears caused by the neurodiversity of this social group, which includes both persons with extensive disorders as well as autonomously functioning ones. Parochialism in perception of the latter group deprives the Polish state of the potential that is difficult to overestimate, which is characteristic of some persons with autism not employed in Poland during the digital era, the time of digitization, automation, remote work on platforms, individual or team work.

Key words: employment, autism spectrum disorder (ASD), rights of persons with disabilities, digital age

Brak zatrudnienia wobec osób z zaburzeniami ze spektrum autyzmu w polskiej rzeczywistości prawnej i cyfrowej

Konwencja o Prawach Osób Niepełnosprawnych, przyjęta przez Organizację Narodów Zjednoczonych w 2006 roku, zapewnia wszystkim osobom z niepełnosprawnością równość wobec prawa i zakazuje wszelkiej dyskryminacji. Gwarantuje również prawo do pracy. Kwestia zatrudniania osób autystycznych doczekała się wielu opracowań naukowych w literaturze anglojęzycznej, podczas gdy w polskiej nauce obszar ten jest wciąż słabo zbadany i opisany. Osoby autystyczne stanowią wyzwanie dla polskiej edukacji i zatrudnienia na otwartym rynku pracy. U źródeł tych problemów leżą uprzedzenia i lęki społeczne spowodowane zróżnicowaniem tej grupy społecznej, w której znajdują się zarówno osoby z rozległymi zaburzeniami, jak i samodzielnie funkcjonujące. Zaściankowość w postrzeganiu tej drugiej grupy pozbawia państwo polskie trudnego do przecenienia potencjału, jakim charakteryzuje się część osób z autyzmem niezatrudnionych w Polsce w czasach cyfryzacji, automatyzacji, pracy zdalnej na platformach, pracy indywidualnej czy zespołowej.

Słowa kluczowe: zatrudnianie, zaburzenia ze spektrum autyzmu, prawa osób z niepełnosprawnościami, era cyfrowa

Introduction

A person with autism spectrum disorders (a person with ASD¹) can be a potential employee if two basic conditions are met. Firstly, their level of social functioning must be developed enough, for example in the process of rehabilitation, to be able to be independent or require only little support from other people. Secondly, an employer must be willing to employ a person (while meeting the formal requirements) whom science defines as neurodiverse² (Singer 1998, 1999). This text is devoted to the problem of not employing high-functioning persons with ASD on the Polish open job market in the digital era in which we all live. Digital age is defined by the Cambridge Dictionary as "the present time, in which many things are done by computer and large amounts of information are available because of computer technology" and "the present time, when most information is in digital form, especially when compared to the time when computers were not used" (https://dictionary.cambridge.org/dictionary/english/digital-age). In their neurodiversity, persons with ASD are equipped with features that not only allow them to perceive reality in an unconventional way, but also to obtain and analyse data in an unusual way. This is a potential that no country can afford to lose. The digital age offers unlimited possibilities of employing a person whose job position can be both local and global. The digital age brings challenges to job markets in three areas: automation, digitization and online job platforms described and interpreted with data in the Eurofound report, published in 2021. "This report provides a snapshot of how these vectors influence employment, work and social dialogue. It concentrates on key emerging issues and derives policy pointers from them" (Eurofoud 2021, p. 1). Work in the digital age is, like any job, a source of economic independence, fulfilment and competence as well as facilitation of the process of socialization. "For adults with ASD the motivation for engaging in employment is no different to those of the general working population. Every individual with and without a disability has the right to work, to freely choose their employment, to work in just and favourable conditions and to be protected against unemployment" (Scott et al. 2017: 1).

ASD – Autism Spectrum Disorder. A person with ASD can be a person with deep and extensive disorders, requiring constant care and nurturing. Or they can be high-functioning persons, able to function independently in social life. The article is devoted to the latter social group.

The term "neurodiversity" was introduced to science by Judy Singer in 1998, in her thesis in sociology.

"A personal exploration of a New Social Movement based on Neurological Diversity"³

Neurodiversity is a feature of the human species and concerns recognizing that our brains, through thinking, attention, perception, memory and the way of communication (cognitive processes), perceive the surrounding world in a neurologically diverse way. Thus, the human species is not divided into "normal" and "abnormal" individuals, but into neurodiverse (e.g. a person with bipolar affective disorder, autism, dyslexia) and neurotypical (a person not characterized by neurodiversity) (cf. Silberman 2017; Singer 2017). In her description of neurodiversity, Singer had in mind primarily persons with autism, and the term was created to:

"In summary, my original conception of Neurodiversity was as

- an addition to the categories of intersectionality thus an analytical lens for examining social issues such as inequity and discrimination
- an umbrella term as a possible name for a civil rights movement for the neurological minorities beginning to coalesce around the pioneering work of the Autistic Self-Advocacy Movement" (Singer 2020).

The pioneering social movement of autistic self-advocates (ASD self-advocates) has become a reality in Western Europe since the 1990s (Leadbitter et al. 2021). It grew in the 1960s and 1970s from the social civil society movement of persons with disabilities in the USA and the movement of disabled people fighting for their rights in Great Britain (Rapaport et al. 2005; Oliver 2013). "Disabled people have been abstracted from society and as an abstraction we embody the essence of social relationships at a particular point in historical time" (Finkelstein 1997).

In Polish social reality, the movement of autistic self-advocates is not massive and does not cover the whole country. It remains at the stage of activities of non-governmental organizations associating persons with ASD and their active parents. There are a number of factors contributing to this state of affairs. First of all, Poland has different historical conditions than the USA and Western Europe. Until 1989, the so-called social model of disability did not exist in the Polish political system (cf. Oliver 2013). During the communist era, we were fascinated by the medical model that saw in a person with a disability only a lack, deficit or disability that could be eliminated with the help of medicine (e.g. pharmacology) or medical rehabilitation (e.g. prostheses). The People's Republic of Poland did not favour persons with disabilities and locked them in hospitals, rehabilitation centers or houses from which it was often impossible to go out into the street. At that time, the conceptualization of disability was carried out through barriers: in the damaged body, architectural, social or mental barriers of the persons concerned.

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This was the title of one of the chapters in Singer's thesis (1998).

After 1989, the processes of changing social stereotypes and prejudices, which have lasted until today, began. Still, the consequence of superstitions, intolerance and social fears is the treatment of, among others, persons with autism spectrum disorders as incapable of professional work, even in the digital age.

In Poland of the 21st century, Neurodiversity as a social movement is practically non-existent. We even have difficulties with the term itself, in its social interpretation. This problem does not concern only our society or representatives of Polish science, not to mention decision makers. "Fundamentally, neurodiversity emphasizes the collective strength inherent in cognitive diversity (Chapman 2020) and that this strength arises from all kinds of differences, including those associated with autism, intellectual disability or language impairment (Kapp 2020)" (Leadbitter et al. 2021: 2).

Autism Spectrum Disorder is neurodevelopmental and holistic. This means that it applies to all cognitive processes and the entire functioning of a person with autism. In Poland, this disorder is diagnosed by a psychiatrist, who can use the support of a speech therapist, clinical psychologist or special educator. Autism spectrum diagnosis in Poland is carried out by psychological and pedagogical counselling centres or private diagnostic and therapeutic centres specializing in the assessment of this disorder. The diagnosis mainly concerns three spheres of functioning of a child, an adolescent or an adult: the sphere of social contacts (difficulties in relations with other people, lack of ability to sustain them), the sphere of communication mainly verbally and the sphere of repetitive behaviour patterns such as motor stereotypes, narrow range of interests and routinisation of everyday activities (Pisula, 2010). Each person with autism spectrum disorders is different and has their own individual personality and character traits. They also have their individual biography which shapes their behaviour and attitudes. In this biography, there may be a chance for an early diagnosis and an immediate process of psychological, pedagogical, pharmacological or social rehabilitation. It may also happen that the diagnosis was made not until in early adulthood, and a person with ASD (especially a woman) masked their disorder, consciously or unconsciously hid and concealed themselves in the world, trying to adapt to others in order to be able to coexist with them (cf. Nerenberg 2022).

Data on the prevalence of the autism spectrum in the population have an upward trend. Interesting facts come from the Educational Information System (EIS) of the Polish Ministry of Education and Science⁴, which show an increase in

⁴ The legal basis for the functioning of the Educational Information System (EIS for short) are:

⁻ Act of 15 April 2011 on the educational information system (Journal of Laws of 2018, item 1900, as amended),

⁻ Regulation of the Minister of National Education of 28 August 2019 on the detailed scope of domain

the number of students with special education certificates issued due to autism spectrum disorders in the last five school years:

- 2017/2018 16 098,
- 2018/2019 21 150,
- 2019/2020 21 242,
- 2020/2021 27 659,
- 2021/2022 36 189 (https://autyzmwiedza.pl/jak-czesto-wystepuje-autyzm/).

This comparison shows that the rate of occurrence of these disorders is increasing, which may be due to precise diagnostics, changes in the criteria for its use and the still scientifically unexplained aetiology of this disorder. In the USA, the ASD prevalence rate is 1 in 36 children aged 8 years and over (MMWR 2020), and in Europe it is 1 in 100 children and it depends on the country and region. Data for Europe and Poland are still not precise. Differences in the prevalence of the autism spectrum may result from methodological discrepancies, but also from differences in population parameters (Frombonne 2018). Their estimated value allows for an unequivocal statement that in the coming years we will be dealing with a large group of persons with ASD in Poland who will be interested in entering the open job market.

Rights of persons with autism spectrum disorders

In 2006, the United Nations adopted the Convention on the Rights of Persons with Disabilities, which was ratified by Poland in 2012. The Convention was developed in the spirit of the social model of disability, locating human disability in the barriers created by the surrounding society. According to Finkelstein, "it is society that makes us disabled, and persons with disabilities are victims of social oppression" (Finkelstein 2001, p. 5). "Michael Oliver, one of the pioneers of this way of thinking, argues that disability is a particular social situation that has nothing to do with the body. Finkelstein, on the other hand, defines biological impairment as a prerequisite for disability" (Ciszewski 2019, p. 6). The Convention is a legal act based on the idea of human rights developed in the form of a disability model based on these rights by Degener (2017). The author explains with consistency the right to dignity of persons with disabilities, placing this social group on an equal footing with other groups, with particular emphasis on the so-called able-bodied majority. Degener repeatedly emphasizes that persons with disabilities do not fully enjoy their civil, political, economic and other social rights, which is an undoubted violation of their right to respect for dignity. Degener writes

about the exceptional importance of the Convention and its role in guaranteeing the equal status of persons with disabilities. The Convention has a whole range of measures that can ensure this status. One of them is the right to work, without discrimination and under just and favourable conditions.

The Convention became an implication for the creation of legal acts and recommendations in the European Union:

- Council Decision of 26 November 2009 concerning the conclusion, by the European Community, of the United Nations Convention on the Rights of Persons with Disabilities (2010/48/EC).https://eurlex.europa.eu/legal-content/ EN/TXT/PDF/?uri=CELEX:32010D0048&rid=1
- Communication from the Commission to the European Parliament, the Council, the European Economic and Social committee and the Committee of the Regions, European Disability Strategy 2010-2020: A Renewed Commitment to a Barrier-Free Europe. COM (2010) 636 final. https://eur-lex. europa.eu/LexUriServ/LexUriServ.do?uri=COM:2010:0636:FIN: EN:PDF
- Resolution ResAP(2007)4 on the education and social inclusion of children and young people with autism spectrum disorders adopted by the Committee of Ministers on 12 December 2007 at the 1014th meeting of the Ministers' Deputies. https:// search.coe.int/cm/Pages/result_details. aspx?ObjectID= 09000016805b039a.

Particularly noteworthy is the annex to the last-mentioned resolution, which states: "Persons with autism spectrum disorders are full citizens of Europe. If provided with the appropriate level of education, they can be integrated into, and contribute to, society" (Appendix to ResolutionResAP(2007)4).

Due to difficulties in social functioning and problems with communicating with other people, high-functioning persons with autism spectrum disorders end their active participation in Polish social life at the moment of graduating from primary or secondary school. Some of them undertake studies at a university, where they often do not receive proper and individualized support. These persons left without assistance fall into the trap of isolation and do not take up employment on the open job market. It is a measurable loss for the Polish state in the form of costs incurred for the rehabilitation and education of this social group, ultimately isolated in family homes or care institutions. It is also an immeasurable loss as the potential of those persons is wasted due to the fact that they take up work below their qualifications and above-average skills.

The report of the Supreme Audit Office (2019) on supporting persons with ASD in preparing them for independent living clearly states that in Poland there is no professionally functioning support system in the adult life of this social group. The institutions existing in the Polish legal reality (for example social welfare homes or occupational therapy workshops) do not meet this requirement.

Only non-governmental organizations dealing specifically with persons with autism are able to support them in their adulthood. Foundations and associations have a vision of this support and are able to provide it. Unfortunately, they lack the financial resources to achieve their goals. The report also draws attention to the lack of statistical research related to students with ASD in the first and second cycle studies, master's studies and doctoral studies. The Supreme Audit Office (SAO) confirms that these persons are admitted at Polish universities, but it is not known how many of them continue studies and graduate from university. Completion of higher education does not mean that autism spectrum disorders are over. Persons with ASD continue to struggle with their individual autism-related difficulties and continue to require support, including when entering the open job market.

The right to work of persons with autism spectrum disorders

The 11th edition of the International Classification of Diseases and Related Health Problems notes that: "Autism spectrum disorder is characterized by persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour and interests" (ICD-11 2022). This is the most general characteristic of autism spectrum disorders, which, due to the scientifically unexplained aetiology, still remain very enigmatic. They are a complex medical construct caused by the interaction of genetic, environmental and immunological factors (Jiang et al. 2022). The picture of a high-functioning person with ASD cannot be complete if we describe only the negative symptoms of this disorder and their consequences for social functioning. ASD also has positive sides. A person on the autism spectrum has the ability to analyze the surrounding reality in a highly unconventional way, which is often used when employing this group in architectural studios or in the IT industry. Steve Jobs said at the end of his career that everyone he had worked with at the beginning of his career was a mismatch. This is one of the extremely accurate descriptions of persons with ASD, whose memory can be larger than the accepted norms, and at the same time the senses send a person with ASD contradictory signals. Most often, persons with ASD are perfectionists, which is a consequence of an unnatural adherence to the constancy of place, time and activities related to them. They are very systematic with exceptional abilities related to data analysis and the development of new, innovative solutions. Their mismatch/incompability is the basis for searching for new ways in

⁵ The best-known Polish organizations dealing with persons with ASD are: SYNAPSIS, W Spektrum Życia, JiM, Przystanek Autyzm Foundation and many others.

science, inventing unusual improvements or looking for original patterns. Persons with ASD "see" neurodiversely.

These qualities mean that some persons with ASD should be extremely attractive to employers on the open job market, not only in Silicon Valley, but also in Poland. These features should be noticed and developed already in primary school, secondary school and college. This is a resource that the state cannot underestimate and ignore. The introduction of the spectrum category into the name of ASD, which is therefore a broad concept covering various types of autistic disorders, is not without significance. There is a large proportion of persons with ASD who do not have this potential. These include persons on a spectrum that has combined with intellectual disabilities, a complete lack of verbal communication, or rare genetic syndromes such as Rett⁶ syndrome or fragile X⁷. This group requires full support and the need to create conditions for a dignified existence, and has nothing to do with the open job market.

Unfortunately, in Polish system of education, persons with ASD are treated as a problem at every stage, including higher education Already in kindergarten, children diagnosed with ASD are a challenge for the teaching staff and for the parents of the so-called healthy. Teachers from kindergartens, primary and secondary schools do not know how to educate a child or a young person who has been diagnosed with the autism spectrum. First of all, this is due to the fact that the standard of education preparing for the teaching profession at Polish universities is not adjusted to the requirements of reality⁸. It lacks the compulsory package of knowledge, skills and social competences in the field of special education, theoretical and practical science about a person whose development is different from the accepted norms (cf. Grzegorzewska 1968). In practice, this means that the future kindergarten or school teacher does not have classes on the methodology of educational and therapeutic work with persons with various types of disabilities, chronically ill (including mental disorders and diseases), having problems with complying with social and legal norms, with speech or highly gifted. This state of affairs is the beginning of problems if there is a child with ASD in a kindergarten or class group. Secondly, in Poland there is no inclusive education understood as an idea and a way to educate diverse groups. "The concept of inclusive education is more precisely characterized by the following features: access to school for all students, balanced educational goals, taking into account the harmonious development of students, a flexible system of support for cooperating

of education preparing for the teaching profession (Journal of Laws 2019, item 1450).

⁶ Rett Syndrome is a rare, devastating genetic disorder that is predominantly female-linked. It is a neurodevelopmental disorder affecting the functioning of the brain, spinal cord and nervous

Fragile X syndrome is an incurable genetic disease that is often the cause of intellectual disability.
See – Regulation of the Minister of Science and Higher Education of 25 July 2019 on the standard

specialists and a common educational programme" (Szumski 2019: 14). This idea assumes that everyone is diverse and classes in schools are not composed of children with and without disabilities, but of persons with diverse minds. Each person in such a class receives support, and the way of teaching is far from transferring encyclopaedic knowledge or lectures by the teacher at the blackboard. The method of introducing inclusive education by the Polish state is currently committing a crime against this idea. In fact, this is a model of introducing a student with a disability to a class, which has been developed in Poland for years in the form of integrated education. "Integrative education (especially that burdened with the features of the borderland reduced only to the clash of two cultures and their competition) is conducive to generating difficult situations, e.g. shaping the ability to use one's disability in order to lower requirements (in accordance with the essence of pathological resourcefulness), building internal boundaries that put in opposition able-bodied and disabled students, and as a result, creating a rejecting attitude towards the latter, or generating a climate of misunderstanding and a sense of injustice" (Gajdzica 2015: 126). This is model that has failed. This time it will be called inclusive education, in which the number of persons in the class will not have to be reduced, and therefore it will be cheaper. And it seems that is all it is about. It is worth recalling that as early as in 1994, in the introduction to the declaration submitted at the UNESCO World Conference in Salamanca (Declaration of Salamanca), the idea of education for all, especially for children with special educational needs, was written down (http://rownosc.info/media/uploads/declaration from salamanca.pdf). This idea is close to Polish special education propagated almost twenty years earlier by Hulek, who believed that the needs of persons with disabilities and those without disabilities are practically the same.

The Act of 19 July 2019 on ensuring accessibility for persons with special needs (Journal of Laws of 2019, item 1696) introduced in Poland in all public entities is just a slow step in the right direction. This is only the beginning. Unfortunately, the Act does not specify the term "person with special needs". According to the legislator, this is a person "who, due to their external or internal characteristics, or due to the circumstances in which they find themselves, must take additional actions or apply additional measures in order to overcome the barrier in order to participate in various spheres of life on an equal basis with other persons" (Act 2019: 1) and who must be ensured architectural, digital and information and communication accessibility in a public entity. The legislator did not specify (also in lower-level acts) how the accessibility of a public entity for persons with ASD should manifest itself. This lack of precision had a negative impact on the actual functioning of this group, for example, at state universities which interpret the act individually and try, or not, to make the university an entity accessible to this group of students.

The educational path of a person with ASD in the Polish education system, including higher education, is not easy. Will they find enough strength and determination to enter the open job market with their qualifications and extraordinary potential? The interpretation of the report prepared by the Public Opinion Research Centre for the JIM Foundation on the social image of a person with autism brings hope. Optimistic data appeared in it. Nearly 62% of adult Polish women and men believe that persons with autism are able to work professionally and 62% of respondents declare that they would employ these persons if they met the formal requirements. It should be added that very young people, aged 18-24, would opt for such a solution (Social picture of autism 2021).

Conclusions

The Convention on the Rights of Persons with Disabilities gives persons with ASD the right to work. This is one of the fundamental rights. The job market is becoming a flexible market where, apart from traditional forms of meeting professional challenges, remote forms exist and new ones will probably be created. This is because man develops their intellectual and adaptive abilities in accordance with the assumptions of Piaget's theory. A person adapts through two processes: assimilation (adjusting to new conditions using old patterns) and accommodation (producing new patterns or changing existing ones - see Covid-19 pandemic) (Piaget 1966). Piaget set the goal of education to create people capable of innovation, creative, thinking outside the accepted patterns, and at the same time verifying and critical (Piaget 1985). The assumptions of this goal are consistent with the characteristics of persons with ASD who do not co-exist with other disabilities, i.e. persons described as high-functioning or with Asperger's syndrome. This is a group of innovative people, unconventional in thinking, talented, although they may have problems with social interaction. These are meticulous individuals, able to perform routine tasks that are tiring for others. They are willing to work on numbers and develop statistics. Therefore, jobs should be prepared for these persons on the open market so as not to lose their valuable potential. In the digital era, which gives practically unlimited possibilities of self-realization in various professions, in teams and in individual work, these jobs should be easier to prepare. In the digital age, tools are given to people for whom modern technologies are something obvious. A group of employees with ASD can use these instruments to work efficiently for their independence as well. "During the past few decades, a variety of technologies, such as tactile prompting, picture guiding, audio cuing, video modelling, computer-aided instruction, virtual reality, and robotics, have been developed and implemented among individuals with ASD for different training purposes (DiGennaro Reed et al. 2011; Goldsmith and LeBlanc 2004; Hopkins et al. 2011; Parsons 2006)" (Chen et al. 2015).

Technologies provide the opportunity to conduct conversations, serve customers, order purchases, receive informational, emotional and legal support, develop and conclude contracts, prevent cybercrime, track parcels, surveillance, design cities, gardens, spaces, etc. Technologies should go to persons with ASD prepared to work in process of educating and to meet with an employer who is economically encouraged and aware of the resources and difficulties of persons with ASD. The digital era offers virtually unlimited possibilities that can be fully used when employing persons with ASD, even those who do not speak and use programmes such as MÓWIK. Unfortunately, the digital age will not solve the problem of the state not having a vision of using human potential. The state must deal with this on its own, and so must the Polish state.

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