



Person on the Autism Spectrum on (the margin of) the Labour Market

The Nominal International Standard versus the Reality of a European Union Member State – (The Example of Poland)

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Abstract

Autism is a spectrum disorder (abbreviated ASD – autism spectrum disorder), which encompasses a variety of developmental challenges in communication, thinking, cognitive skills, interests, and forms of activity, as well as motor skills. Ensuring that people with autism spectrum disorder realise their right to work seems to be a problem in Poland, contributing to their discrimination. The aim of the paper is to present the issue of employment of adults on the autism spectrum in Poland as a member state of the European Union in the light of the international standard. The article discusses the objective and subjective approach to adults with ASD in Poland, the legal conditions

of their employment (including international law), as well as the results of empirical research and conclusions in this respect.

Keywords

autism – ASD – disability – employee – employer – human rights

1 Introduction

The aim of the article is to establish a standard of the international right to work of people on the autism spectrum in comparison with its implementation in a European Union member state, using Poland as an example. Poland, as a member state of the European Union and a party to many international agreements on human rights protection, should counteract discrimination on the labour market regarding persons with disabilities and generally does so, but autistics are the group that is overlooked and even secondarily discriminated against among other persons with disabilities. The authors present the objective and subjective approach to autism (the latter as a result of the co-authorship of a researcher on the autism spectrum), the international and Polish legal conditions of the right to work of persons with disabilities, including persons with autism spectrum disorder (ASD), and a practical approach expressed by the results of empirical research covering occupational activity establishments functioning in Poland as one of the elements of the protected labour market, which are assumed to provide employment for persons with significant and moderate disabilities, including ASD. Finally, conclusions relating to Polish and international law are presented in relation to the problem of employment of persons with autism spectrum disorder.

2 Initial Reflection – An Objective One

Autism is a spectrum disorder (abbreviated ASD – autism spectrum disorder), which encompasses a variety of developmental challenges in communication, thinking, cognitive skills, interests, and forms of activity, as well as motor skills. The severity of individual difficulties on the different dimensions of the spectrum varies considerably from person to person and can result in both profoundly impaired functioning in some people and allow for completely

independent functioning in others with less severe symptoms. It makes people physically disabled, but also communicatively disabled, which in turn makes them socially disabled. A person without a relationship with society vegetates, struggling for every aspect of the relation.¹ The real world in relation to people on the autism spectrum is brutal, even though the human rights to which they are entitled have a universal and timeless meaning, a universal, inherent, inalienable, inviolable, natural and indivisible nature (as with any human being). However, one man's right may end where another's begins.² The autistic finds themselves at a disadvantage here.

The diagnosis that autism is becoming the civilisational challenge of the 21st century adds to the seriousness of the situation. When the exception turns into the rule – any shortcomings justified by statistics are clearly outdated. This should also be the case with the status of autistic people, especially in the era of the development of human rights, anti-discrimination law or the concept of accessibility. People affected by this dysfunction should not be *de facto* deprived of the basic rights that every human being shall enjoy. These rights and privileges should be respected so that someone's ignorance, fear or prejudice or collective desensitisation does not squander the potential of a person with autism.

The right to work is perhaps not spectacular, but nevertheless one of the key human rights.³ This is because work provides material and personal independence, a sense of satisfaction and self-fulfilment. It assumes particular importance in the case of people with disabilities, whose dysfunctions significantly determine their chances for employment. Ensuring appropriate working conditions for people with disabilities helps to reduce social costs compared to maintaining their professional inactivity. Of particular relevance here is employment support for people on the autism spectrum, who appear to be

1 American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders* (5th ed, 2013). <https://doi.org/10.1176/appi.books.9780890425596.744053>.

2 Maciej Oksztulski, *Prawnomiędzynarodowe standardy prawa do nauki i ich praktyczna realizacja przez krajowe instytucje naukowe w odniesieniu do studentów z spektrum autyzmu. Analiza porównawcza ze szczególnym uwzględnieniem Polski i Stanów Zjednoczonych* [International Standards for the Right to Education and their Practical Implementation by National Academic Institutions with Regard to Students on the Autism Spectrum. A comparative analysis with special reference to Poland and the United States] (2021) p. 25, available at <https://repozytorium.uwb.edu.pl/jspui/bitstream/11320/12554/1>.

3 More widely: Temple Grandin, *Choosing the Right Job for People with Autism or Asperger's Syndrome*, November 1999, available at <https://www.iidc.indiana.edu/irca/articles/choosing-the-right-job-for-people-with-autism-or-aspergers-syndrome.html>; *Support at work – a guide for autistic people*, available at <https://www.autism.org.uk/advice-and-guidance/topics/employment/support-at-work/autistic-adults>.

somewhat excluded from the labour market, even in relation to people with disabilities in general.⁴

An excellent trial (a kind of test) of the approach of legislators towards autistic people is the issue of employment, where it is not about yet another welfare benefits, but about systemic safeguards for the possibility of offering (by autistic people) solid work for a reasonable wage (from the employer), to the mutual benefit (of the employee and the employer). Solutions must be sought especially in the law, which is the best regulating measure. This is expressed in its constant improvement (as realities change, law also changes in relation to realities – accordingly, not directly). This, of course, does not mean constant variability, but variability that is socially justified. Let us assume that ensuring non-discriminatory employment opportunities for people with autism should be part of the public interest of modern societies.

3 Initial Reflection – A Subjective One

The term ‘autistic’ seems sad, but not pejorative. It is difficult to judge how much of this is human merit, but a non-stigmatising designation has been achieved here. This does not change the fact that an autistic person has a difficult life. Even more difficult the more they interact with their social environment. This communication paradox implies a dichotomy – either growing alienation or a constant struggle – against barriers, against themselves, against the system’s human opportunism ... First the family, then education and finally the labour market. After all, each of these stages is not easy for anyone. Failures come here and there, more or less frequently. Improvements in legislation generally take it into account and provide standard safeguards. However, it is hard to resist the

4 As a rule, people with autism benefit from the existing system of support in the area of health care, social assistance, education, and social, vocational and employment rehabilitation of people with disabilities to a very poor degree in relation to their needs. The extent and nature of support should be differentiated and individualised, tailored to age, level of intelligence, depth and type of disorder and co-morbidities, and it is unfair to include autistic people among the mentally ill or mentally handicapped. The same is the case at the level of higher education, where Maciej Oksztulski, in his doctoral dissertation entitled *Legal Prawnomiędzynarodowe standardy prawa do nauki i ich praktyczna realizacja przez krajowe instytucje naukowe w odniesieniu do studentów z spektrum autyzmu. Analiza porównawcza ze szczególnym uwzględnieniem Polski i Stanów Zjednoczonych* [International Standards for the Right to Education and their Practical Implementation by National Academic Institutions with Regard to Students on the Autism Spectrum. A comparative analysis with special reference to Poland and the United States] (2021) in the concluding argument emphasises ‘secondary discrimination’ pp. 250–253, available at <https://repozytorium.uwb.edu.pl/jspui/bistream/11320/12554/1>.

impression that in the case of autistics there are many more failures.⁵ The family usually stops at the stage of parents and siblings (only high-functioning people without speech dysfunction etc. try to start their own families).⁶ Education is doing somewhat better, as primary education has become quite common for autistics, and it is not particularly surprising for an autistic to graduate from high school these days either. There is also a noticeable increase in the number of individuals with autism entering higher education.⁷ Individuals are climbing further up the educational ladder.⁸ Up to the glass ceiling generally.

For it appears that a paradigm of humanitarianism rather than rational functionalism has apparently been applied to education. Education on the basis of an appreciative, long-term positioning in the social hierarchy, on the one hand, brings the disadvantage of arousing aspirations and providing a false sense of common following the general public. On the other hand, when an autistic person tries to make use of the education he or she has received – there is a disappointing clash with the reality of the labour market. It is very rarely otherwise,⁹ but this needs to change.

5 Ewa Pisula, Karolina Ziegart-Sadowska, "Broader autism phenotype in siblings of children with ASD – a review", 16(6) *Int J Mol Sci.* (2015) pp. 13217–58. <https://doi.org/10.3390/ijms160613217>.

6 Stefan N. Hansen *et al.*, "Recurrence Risk of Autism in Siblings and Cousins: A Multinational, Population-Based Study," 58(9) *J Am Acad Child Adolesc Psychiatry* (2019), pp. 866–875. <https://doi.org/10.1016%2Fj.jaac.2018.11.017>; Linda Ejlskov *et al.*, „Prediction of Autism Risk from Family Medical History Data Using Machine Learning: A National Cohort Study from Denmark," 1(2) *Biological Psychiatry Global Open Science* (2021) pp. 156–164. <https://doi.org/10.1016/j.bpsgos.2021.04.007>.

7 Jessica N. Cadette *et al.*, "The Effectiveness of Direct Instruction in Teaching Students with Autism Spectrum Disorder to Answer „Wh-“ Questions," 46 *J Autism Dev Disord*, (2016) pp. 2968–2978. <https://doi.org/10.1007/s10803-016-2825-2>.

8 Through doctoral studies or gaining further areas and levels of education.

9 Successful individuals include Temple Grandin – Doctor of Animal Science and Professor at Colorado State University, a person on the autism spectrum. A tireless populariser of autism spectrum knowledge, she is the author of many bestsellers. She participated in the training conference „Fascynujące umysły – niezwykle spotkania z osobami ze spektrum autyzmu" [Fascinating Minds – extraordinary encounters with people on the autism spectrum] on 28–29.09.2021. Warsaw, together with self-advocates on the autism spectrum with university degrees. These young people presented their experiences, successes, failures as well as the challenges they face in the papers they gave. Each of these people is working to change perceptions of the autism spectrum, and for some time they have been doing so together with the SYNOPSIS Foundation. Justyna Pawlak, MA (special teacher), Maciej Oksztulski, MA (currently Doctor of Law – researcher), Kacper Rudak, MA (currently holds two MA degrees) – see the SYNOPSIS Foundation online training conference "Fascynujące umysły – niezwykle spotkania z osobami ze spektrum autyzmu" [Fascinating minds – extraordinary encounters with people on the autism spectrum] – Training calendar (mp.pl), available at <https://szkolenia.nia.mp.pl/zjazdy/szkolenia/show.html?id=17059>.

Maciej Oksztulski is the first non-verbal autistic person in Poland who passed the Matura exam,¹⁰ after which he graduated from law school,¹¹ defended his doctoral dissertation in legal sciences¹² and, with the support of many people and no small amount of luck, found employment at a university,¹³ in a non-governmental organisation,¹⁴ and regularly benefits from competitive research grants.¹⁵ Maciej Perkowski is his supervisor (MA and PhD theses), as well as

10 He passed his baccalaureate exams in 2010 and was awarded a university degree, as the first non-verbal autistic person in Poland – see Magdalena Szymańska-Smarżewska, „Maciek chory na autyzm studiuje prawo, zna sześć języków i ma IQ 140” [Maciek with autism studies law, knows six languages and has an IQ of 140], *Kurier Poranny*, 13 November 2010, available at <https://poranny.pl/maciek-chory-na-autyzm-studiuje-prawo-zna-szesc-jezykow-i-ma-iq-140/ar/5344768>.

11 On 2.06.2015, he defended his Master of Laws degree with a very good result.

12 See: Maciej Oksztulski, official website, available at <https://oksztulski.uwb.edu.pl/>; Maciej Oksztulski, Faculty of Law, University of Białystok, available at <https://prawo.uwb.edu.pl/pracownicy/adiunkci-i-asystenci/dr-maciej-oksztulski>.

13 Dr Maciej Oksztulski is a research fellow at the Faculty of Law of UwB, the only non-verbal person on the autism spectrum with a severe disability in Poland to receive a doctorate in law. His research relates to international and EU law in its broadest sense, analysing the legal aspects of human rights, the rights of persons with disabilities and, in particular, the rights of persons on the autism spectrum (ASD). A number of his achievements has been already established during his studies during his academic work and doctoral studies. His achievements, despite his short academic career, stand out from those of other representatives of the younger generation of legal researchers (despite his disability). This is primarily due to his openness to interdisciplinary research – Maciej Oksztulski, official website, available at <https://oksztulski.uwb.edu.pl/>; Maciej Oksztulski, Faculty of Law, University of Białystok, available at <https://prawo.uwb.edu.pl/pracownicy/adiunkci-i-asystenci/dr-maciej-oksztulski>.

14 Maciej Oksztulski is a data analyst in the Europe Direct Podlaskie project due to his unique skills. He helps the whole team analyse EU legislation. He prepares summaries of the rulings of the Court of Justice of the European Union for the point's website – see: Europe Direct Podlaskie, *Maciej Oksztulski i Maciej Perkowski byli gośćmi audycji radia Tok FM*, available at <https://edpodlaskie.eu/zespol-ed-podlaskie-w-audycji-radia-tok-fm/>.

15 Together with other researchers from UwB, he triggered a broad scientific discussion on the rights of adults on the autism spectrum. In 2017–2018, he participated as a researcher and research subject in the project entitled. “NO-AUTism! Kształcenie i rozwój personalny doktoranta z autyzmem – status quo i interdyscyplinarna optymalizacja perspektyw społecznych i zawodowych” [NO-AUTism! Education and personal development of a doctoral student with autism – status quo and interdisciplinary optimisation of social and professional perspectives]. As part of this project, from 12–19 November 2017, he completed a research internship in the USA (Syracuse University – Faculty of Law and Faculty of Education) overcoming another barrier (this time related to a long flight), resulting in a cooperation that continues to this day. In 2020, he was awarded a grant in the Prelude 19 Competition, National Science Centre (Narodowe Centrum Nauki, NCN), funding in the amount of PLN 74,532.00. *Uprawnieni teoretycznie? Status prawny osób ze spectrum autyzmu na rynku pracy (w ujęciu krajowym, międzynarodowym i porównawczym)*

mentor, manager and co-implementer of the grants.¹⁶ Wojciech Zoń supports organisational processes related to the implementation of the aforementioned grants by becoming involved in research in selected areas. It, on the one hand, determines personal commitment to the issues in question and, on the other hand, brings valuable cognitive experience and often provides opportunities to influence society (modelling, piloting, inspiring)¹⁷ and legislation.¹⁸ These

[Entitled in theory? The Legal Status of Persons on the Autism Spectrum in the Labour Market (Domestically, Internationally and Comparatively)] as the project manager of project No. 2020/37/N/HS5/02224. Dr Oksztulski's previous experience has allowed him to be one of the originators and now a contractor in the project "Nauka na rzecz efektywnego wejścia na rynek pracy wykształconych autystów" [Science for the efficient entry of educated autistic people into the labour market], No. NdS/551582/2022/2022 implemented by the Law and Partnership Foundation with a value of PLN 607,890.00 under the Science for Society programme of the Ministry of Science and Higher Education. He is also a contractor within the project entitled "Oddziaływanie prawniczych badań podstawowych na kształcenie prawników na przykładzie badań podstawowych finansowanych przez Narodowe Centrum Nauki w Polsce" [Impact of legal basic research on legal education on the example of basic research funded by the National Science Centre in Poland], under the direction of Prof. Dr. Maciej Perkowski, No. UMO-2021/41/B/HS5/03317, within the OPUS programme of the NCN. In addition, Dr Oksztulski has submitted a new application under the OPUS NCN competition entitled [Accessibility of Higher Education and Neurodiversity on the Example of the Implementation of the Right to Education of Students on the Autism Spectrum in Poland], No. 2022/47/B/HS5/01002. See: Maciej Oksztulski, official website, available at <https://oksztulski.uwb.edu.pl/>; Maciej Oksztulski, Faculty of Law, University of Białystok, available at <https://prawo.uwb.edu.pl/pracownicy/adiunkci-i-asystenci/dr-maciej-oksztulski>.

- 16 Maciej Perkowski, Faculty of Law, University of Białystok, available at <https://prawo.uwb.edu.pl/pracownicy/samodzieln-pracownicy-naukow/prof-zw-dr-hab-maciej-perkowski>.
- 17 Maciej Oksztulski's participation in the competition of the Disabled Foundation and becoming a winner of this competition – see: TVN24, „Przyznano nagrody w konkursie „Człowiek bez barier”. Oto lista tegorocznych laureatów”, 7 December 2022, available at <https://tvn24.pl/polska/czlowiek-bez-barier-2022-lista-laureatow-6411891>; University of Białystok, „Dr Maciej Oksztulski z Wydziału Prawa UwB został Człowiekiem bez barier”, 7 December 2022, available at <https://uwb.edu.pl/aktualnosci/dr-maciej-oksztulski-z-wydzialu-prawa-uwb-zostal-czlowiekiem-bez-barier-6728.html>. Participation of M. Oksztulski in the consultation of instruments on social inclusion and vocational rehabilitation of people with disabilities in the Aktywni Niepełnosprawni project, as well as instruments on social inclusion and vocational rehabilitation of people with disabilities in the Aktywni Niepełnosprawni project <https://wlaczeniespoleczne.pl>, as well as instruments on employment in the Włączenie Wyłączonych project were consulted by the Polish National Consultative Council on Disabled.
- 18 M. Oksztulski's work in providing opinions on various activities; consulting documents, external projects as well as speeches at various forums, active participation in consultations, sending comments and opinions so that the voice is the voice of the widest possible community – see Samorzecznicstwo Fundacji Synapsis [Self-advocacy of the Synapsis Foundation]. *Współtworzenie petycji Autyzm. Nie możemy czekać! Petycja w*

issues are not spectacular in terms of image but are instead consistent with the positivist idea of working at the grassroots. This time, they will also – step by step – search for perfection (i.e. adequate security for autists in the labour market) in law and practice.

4 Seeking Excellence in Law – The International Standard for the Right to Work of People with ASD

Dealing with international law on a daily basis, it is easier to understand that the right to work has a universal meaning, finding support in international, regional and national law.

On the issue of the autism spectrum, international law speaks either in general terms or in an overly reticent manner. The Universal Declaration of Human Rights of 10 December 1948, which proclaims modern human rights, states in Article 2 that: “Everyone is entitled to all the rights and freedoms set forth in this Declaration, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”¹⁹ Next, in the article 23 (1) it is established that “Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment”.²⁰ Although the declaration initially was of a soft character, over time it acquired an international legal standing, setting a binding standard. The principles contained therein are considered now to be legally binding on states both as customary international law and as fundamental principles of humanity.²¹ Further general documents

sprawie dorosłych osób z autyzmem do Premiera, Prezydenta, Marszałków Sejmu i Senatu, do wiadomości Ministra Rodziny i Polityki Społecznej oraz Pełnomocnika Rządu do Spraw Osób Niepełnosprawnych [Co-creation of the petition Autism. We can't wait! Petition on Adults with Autism to the Prime Minister, the President, the Speakers of the Sejm and the Senate, for the attention of the Minister of Family and Social Policy and the Government Plenipotentiary for Disability Affairs] (March 2021) available at https://www.petycjeonline.com/autyzm_nie_moemy_czeka_petycja_w_sprawie_doroslych_osob_z_autyzmem. As a *person without barriers*, a person with ASD has been noted by the Office of the President of the Republic of Poland as a future expert on people with disabilities.

19 Universal Declaration of Human Rights, proclaimed by the United Nations General Assembly resolution 217 A (III) in Paris on 10 December 1948, available at <https://documents-dds-ny.un.org/doc/RESOLUTION/GEN/NR0/043/88/PDF/NR004388.pdf?OpenElement>.

20 *Ibidem*.

21 See: Rita Joseph, Human Rights and the Unborn Child (2009), p. 31; United States of America v. Iran, Judgment, ICJ Reports 1980, p. 42, para. 91.

enacted by the UN (and ultimately international agreements binding on the countries that have ratified them) are notably the International Covenant on Civil and Political Rights²² and the International Covenant on Economic, Social and Cultural Rights of 1966.²³ The latter has framed, inter alia, the right to work as “the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts” and this is a universal framing.²⁴ It is impossible to ignore the resolutions adopted at the International Labour Organisation (e.g., Recommendation 169 of 1984 on employment policy, which indicates the need to promote a full, productive and free right to work²⁵). Colm O’Cinneide believes that “The conceptual core of the right to work as defined and set out in these international human rights treaty instruments is easy to delineate. It protects and gives expression to the human interest in engaging in productive labour. This can be viewed as an instrumentalist good, in the sense that combining together with others in work enables individuals to participate as autonomous members of society in the social, economic and political life of their community. It also can be viewed as an intrinsic good, in the sense that humans express themselves and derive dignity from how they interact with their environment through their work”.²⁶ This way of thinking seems particularly relevant to the right to work for people with disabilities.

All the time we are moving here in the general sphere, which implicitly (and therefore weakened by all objective and subjective barriers and limitations) includes autists. The Convention on the Rights of Persons with Disabilities, 13.12.2006, seemed to provide some detail (ratified by Poland in 2012), but this document, too, speaks only indirectly about the right to work of persons on the

22 International Covenant on Civil and Political Rights, adopted on 16 December 1966 by the United Nations General Assembly resolution 2200A (XXI), available at <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-civil-and-political-rights>.

23 International Covenant on Economic, Social and Cultural Rights adopted on 16 December 1966 by the General Assembly resolution 2200A (XXI), available at <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-economic-social-and-cultural-rights>.

24 Maciej Perkowski, and Maciej Oksztulski, „Wyszkolony autysta na polskim rynku pracy a międzynarodowy standard traktowania”, in P. Nowik, I. Sierocka, W. Witoszko and K. Żywolewska (eds.), *Dorobek i rozwój myśli polskiej nauki prawa pracy w świetle wyzwań XXI wieku. Księga dedykowana pamięci Profesora Bogusława Cudowskiego* (2022) pp. 244–247.

25 R169 – Employment Policy (Supplementary Provisions) Recommendation, 1984 (No. 169), available at https://www.ilo.org/dyn/normlex/en/f?p=NORMLEXPUB:12100:0::NO::P12100_INSTRUMENT_ID:312507.

26 Colm O’Cinneide, “The Right to Work in International Human Rights Law”, in Virginia Mantouvalou (ed), *The Right to Work Legal and Philosophical Perspectives* (2014) p. 100.

autism spectrum.²⁷ It is also unfortunate that, although it is an act concerning persons with disabilities, in Article 4.2 it states that: “With regard to economic, social and cultural rights, each State Party undertakes to take measures to the maximum of its available resources and, where needed, within the framework of international cooperation, with a view to achieving progressively the full realization of these rights, without prejudice to those obligations contained in the present Convention that are immediately applicable according to international law”. For the title issue, Article 27 *Work and Employment* seems crucial: “States Parties recognize the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities.”²⁸ Autistics, as persons with disabilities, certainly fall within this standard, but they are still a long way from “positive discrimination”.

Ensuring human rights requires creating the conditions that make this possible: introducing mechanisms for equal opportunities for persons with disabilities and paying attention to their subjectivity. People with disabilities should be entitled to certain specific rights so that they have the opportunity to realise the general standard to which all people are entitled. Over the last 50 years, this latter view has been reflected in international legislation. The special protection of persons with disabilities is therefore manifested, firstly, in the guarantee of the general human rights standard in national laws of a general nature (dedicated to the general population), and, secondly, through the introduction of legislation and other documents of a specific nature dedicated to persons with disabilities. The relevant norms contained therein, on the one hand, unequivocally confirm that particular rights are granted to persons with disabilities – which is not always universally obvious – and, on the other hand, introduce mechanisms to guarantee realisation of these rights and, in specific cases, define rights that are additional, aimed at counteracting or positively discriminating against persons with disabilities. For autistic people to be able to benefit from their nominal rights, it would be necessary to take into account their subject specificity and to plan and introduce adequate enforcement and control mechanisms from this point of view. For the time being, in the queue for “human rights”, they have to choose whether to stand in the “queue” of

27 Convention on the Rights of Persons with Disabilities adopted on 13 December 2006 in Sixty-first session of the General Assembly by resolution A/RES/61/106, available at <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>.

28 See: Article 27 of the Convention on the Rights of Persons with Disabilities.

persons with motor disabilities, or perhaps with mental or intellectual disabilities. The legislator, on the other hand, provides for rules just like toilets (there are toilets for people with disabilities in addition to men's and women's toilets, where gender apparently no longer matters).²⁹

In the search for excellence in law (i.e. adequate safeguards for autistics in the labour market), one should also consider the somewhat closer (from the authors' perspective) the regional perspective of Europe.³⁰ Objectively relevant acts of general application in the European space include in particular: European Convention for the Protection of Human Rights and Fundamental Freedoms,³¹ adopted at the Council of Europe (CoE) in 1950 by the Council of Europe countries, as well as the European Social Charter of 1961.³² The latter, although not as widely publicised – is of particular relevance to people with disabilities as it regulates social rights by referring to the European Convention for the Protection of Human Rights and Fundamental Freedoms. The first part of the Charter contains a catalogue of rights, while the second part details the obligations of states to realise these rights. The European Social Charter contains norms already directly relevant to persons with disabilities, with an indication of certain sets of rights, as in Article 15: "Persons with disabilities

29 See Linda L. Demer, 'The Autism Spectrum: Human Rights Perspectives', 141 (Supplement_4) *Pediatrics* (2018) pp. S369–S372. <https://doi.org/10.1542/peds.2016-43000>; J. Matt Jameson et al, 'Guardianship and the Potential of Supported Decision Making With Individuals With Disabilities', 40(1) *Research and Practice for Persons with Severe Disabilities* (2015) pp. 36–51. <https://doi.org/10.1177/1540796915586189>; Arian Campo-Flores, and Ashby. Jones, 'Abuse plagues the adult guardianship system: allegations of financial abuse and exploitation are common, despite waves of renovation efforts', *The Wall Street Journal* (30 October 2015), available at <https://www.wsj.com/articles/abuse-plagues-system-of-legal-guardians-for-adults-1446225524>.

30 The specificity here is so far-reaching that the doctrine even speaks of a 'European legal space'; in the EC's 2022 report, Isabel Baptista, and Eric. Marlier, *Social protection for people with disabilities – An analysis of policies in 35 countries* (2022), available at http://ec.europa.eu/social/main.jsp?advSearchKey=ESPN_Disability2022&mode=advancedSubmit&catId=22&doc_submit=&policyArea=0&policyAreaSub=0&country=0&year=0, on important issues that countries still need to address in order to make their social protection systems more effective and promote the related rights of persons with disabilities. In addition, the report gives a number of recommendations at national or EU level to address gaps and obstacles in social protection for people with disabilities.

31 Convention for the Protection of Human Rights and Fundamental Freedoms, opened for signature in Rome on 4 November 1950, available at https://www.echr.coe.int/Documents/Convention_ENG.pdf.

32 European Social Charter (ETS No. 35), adopted in Turin on 18 October 1961, available at <https://rm.coe.int/168006b642>.

have the right to vocational training, rehabilitation and vocational and social readaptation, irrespective of the cause and nature of their disability”, or in its elaboration in Part Two, as in Article 9, concerning the right to vocational guidance, or Article 10 concerning vocational training.³³ It is worth citing the wording of Article 15 here, as a model example of specifying in an international legal instrument both a specific right, concerning only persons with disabilities, and the way in which it is to be implemented. It should be emphasised here that the right of persons with disabilities to social rehabilitation and social and vocational readaptation is not an additional right that would violate the principle of equality of human rights, but a right aimed at enabling persons with disabilities to enjoy such universal rights as the right to work, the right to appropriate working conditions and non-discrimination in employment.³⁴ Direct approaches towards autistic people are still not visible, but the European indirect approaches have become more adaptable for autistic people. This trend is particularly evident in the legal order of the European Union, especially resulting from the Union’s orientation towards human rights.³⁵

The EU Charter of Fundamental Rights, following the entry into force of the Lisbon Treaty (on 1 December 2009), has become part of primary law. Consequently, EU citizens can invoke the Charter of Fundamental Rights before the courts. Poland, on the other hand, formally restricted the exercise of these rights (the so-called UK Protocol),³⁶ but in practice this restriction has not (and fortunately!) proved effective.³⁷ Article 21 of the Charter

33 *Ibid*, Articles 9 and 10, and 15.

34 Maria Janowska, „Prawa osób niepełnosprawnych w międzynarodowych aktach prawnych, materiał archiwalny”, 1(1) *Niepełnosprawność – zagadnienia, problemy, rozwiązania*, (2011/2012) pp. 24–45, <http://cejsh.icm.edu.pl/cejsh/element/bwmeta1.element.desklight-1e20e1ca-e7c1-413d-a8e8-a55c169770b4>.

35 Ewelina Tomczyk, „Ochrona praw człowieka w Unii Europejskiej”, *Krakowskie Studia Międzynarodowe* (2019) pp. 157–171. <http://dx.doi.org/10.34697/2451-0610-ksm-2019-4-009>; Robert Grzeszczak, *Pytania prejudycjalne w obszarze praw człowieka. Podręcznik praktyczny dla sędziów* (2019), available at <http://www.hfhr.pl/wp-content/uploads/2019/03/Pytania-prejudycjalne-podrecznik-dla-sedziow.pdf>; Dagmara Kornobis-Romanowska, „Poszanowanie praw podstawowych w państwach członkowskich Unii Europejskiej – w stronę zapewnienia spójnego poziomu ochrony praw człowieka w Europie?”, 100 *Przegląd Prawa i Administracji* (2015) pp. 447–462.

36 Protocol (No 30) on the application of the Charter of Fundamental Rights of the European Union to Poland and to the United Kingdom, OJ C 115, 9.5.2008, p. 313–314, available at <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A12008E%2FPRO%2F30>.

37 Read more: Andrzej Wróbel (ed) *Karta Praw Podstawowych Unii Europejskiej. Komentarz* (2019); Łukasz Bojarski et al. (eds.), *Karta Praw Podstawowych Unii Europejskiej jako żywy instrument. Podręcznik dla prawników* (2014), available at <https://inpris.pl/fileadmin/user>

of Fundamental Rights concerning persons with disabilities prohibits discrimination of any kind. In contrast, its Article 26 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.”

We believe that, from the perspective of the title issue in the European Union legal order, certain trends deserve special appreciation. Firstly, the underestimated non-binding instruments. Their “soft” character compensates for their extensive scope, which often overlaps with issues that have so far effectively escaped positive law. The concept of autism in European Union (EU) law thus first appeared in the non-binding Charter on the Rights of Persons with Autism, adopted by the European Parliament on 9 May 1996.³⁸ In it, the Parliament explicitly stated that autistic people are socially excluded in relation to non-disabled people as well as disabled people. This is an accurate depiction, although non-binding.

Secondly, the rule of law and democracy of the European Union – which is often criticised but which also has its advantages – the rule of law and democracy correctness in the European Union.³⁹ Any EU citizen, acting individually or jointly with others, may exercise his or her right to petition the European Parliament at any time, on the basis of Article 227 of the Treaty on the Functioning of the European Union. Determined parents of people with autism spectrum disorder (ASD) affiliated to the Organisation Autism Europe 2021 submitted the following parliamentary questions to the European Parliament on the petition of people with disabilities:

1. *What will the Commission do to improve the personal development and employment prospects of autistic people?*
2. *What specific measures does the Commission propose to address the quality of life of people on the autism spectrum, their different situations and needs?*⁴⁰

_upload/documents/KPP/e-book_Karta_Praw_Podstawowych_Unii_Europejskiej_jako_zywy_instrument_Podrecznik_dla_prawnikow.pdf.

38 The European Charter of Rights for Persons with Autism signed on 9 May 1996, available at <https://autism.ie/wp-content/uploads/2019/03/Charter-for-web.pdf>.

39 Jacek Barcik, *Ochrona praworządności w Radzie Europy i Unii Europejskiej ze szczególnym uwzględnieniem niezależności sądów i niezawisłości sędziów* (2019); Jan H. Amberg, „Praworządność w Unii Europejskiej – garść refleksji ze szwedzkiej perspektywy”, 13(1) *Krytyka Prawa. Niezależne studia nad prawem* (2021) pp. 179–190. <http://dx.doi.org/10.7206/kp.2080-1084.434>.

40 For more on the petition: <https://www.autismeurope.org/blog/2021/10/07/european-parliament-approves-lesson-learned-from-petitions-by-people-with-disabilities>.

The European Parliament (EP) at its plenary session in Strasbourg on 6.10.2021 endorsed a report on the lessons learned from the petitions of people with disabilities. Autism Europe and Inclusion Europe produced an easy-to-read (ETR) summary of the report, drafted by MEP Alex Agius Saliba of the EP Petitions Committee.⁴¹ It should be stressed that this document has no binding force, it is nevertheless an initiative based on parliamentary legitimacy. Does this satisfy people with ASD and their families? - rather not.

Both the adopted general standards of international law on the right to work, as well as those stemming from obligations binding upon individual states, affect the shape and detail of the guarantees provided for in national law. This is influenced, for example, by membership in particular international organizations, such as the European Union. Membership of the European Union directly or indirectly influences national law and practice. It is worth looking for references to national practice in order to have a complete picture of the issue and to formulate demands for improvement. Considering this, it was done using the example of Poland as an EU member state.

5 Seeking Excellence in Practice – Implementation of the International Standard in National Realities (the example of Poland)

5.1 General Conditions

The legal status of adults with autism, their rights and the system of protection are indirectly defined in a number of Polish legal acts, such as: the Constitution of the Republic of Poland of 1997,⁴² the Labour Code of 26 June 1974,⁴³ Act of 13 June 2003 on Social Employment, Act of 27 April 2006 on Social Cooperatives,⁴⁴ Act of 27 August 1997 on Social and Vocational Cooperatives Rehabilitation and

41 Alex Agius Saliba, *Report on the protection of persons with disabilities through petitions: lessons learnt*, Report – A9-0261/2021, European Parliament, available at https://www.europarl.europa.eu/doceo/document/A-9-2021-0261_EN.html.

42 Konstytucja RP z dnia 2 kwietnia 1997 r. / Constitution of the Republic of Poland of 2 April 1997, Journal of Laws of 1997 no. 78 item 483 as amended.

43 Kodeks pracy z dnia 26 czerwca 1974 r., / Labour Code of 26 June 1974, OJ. 2022 item 1510 as amended.

44 Ustawa z dnia 27 kwietnia 2006 r. o spółdzielniach socjalnych / Act of 27 April 2006 on social cooperatives, Journal of Laws of 2020, item 2085 as amended.

Employment of Disabled Persons,⁴⁵ Act on the Ombudsman of 1987,⁴⁶ as well as the Act on Patients' Rights and Patients' Rights Ombudsman of 6 November 2008.⁴⁷ The document directly relates to persons with ASD in Poland is Charter on the Rights of Persons with Autism, adopted on 13 July 2013 by the Sejm of the Republic of Poland.⁴⁸ Formally, there are regulations in Poland relating to the employment of people with disabilities, which also include autistic people. The specificity of autism has also been recognised to a similar extent, as in the European Parliament. The Sejm of the Republic of Poland has stated that autistic persons are socially excluded not only in relation to non-disabled persons, but also in relation to disabled persons, however, also in this case the Charter on the Rights of Persons with Autism, as a Sejm resolution, does not formally entail legal effects.⁴⁹ Its main function is to draw attention to the fact that persons with autism are persons with specific needs, often different from the needs of other persons with disabilities. This specificity should be taken into account in all regulations governing the support system for persons with ASD in Poland. Other legal regulations and documents are also very important, but due to the volume of the work, they will not be quoted.

It can be estimated that about 2% of the 400,000 autistic people in Poland are working, and that mostly and part-time. Their average labour force participation rate is as much as five times lower than the European Union average of 10%.⁵⁰ This is not a large percentage, despite the existence of a sheltered labor market institution. The employment of people with ASD (albeit only partially) is mentioned in legal acts concerning the activity of Vocational Development Centres (*zakłady aktywności zawodowej, ZAZ*). Vocational Development Centres

45 Ustawa z dnia 27 sierpnia 1997 r. o rehabilitacji zawodowej i społecznej oraz zatrudnianiu osób niepełnosprawnych / Act of 27 August 1997 on professional and social rehabilitation and employment of disabled persons, Journal of Laws of 2023, item 100 as amended.

46 Ustawa z dnia 15 lipca 1987 r. o Rzeczniku Praw Obywatelskich / Act of 15 July 1987 on the Ombudsman, Journal of Laws of 2020, item 627 as amended.

47 Ustawa z dnia 6 listopada 2008 r. o prawach pacjenta i Rzeczniku Praw Pacjenta / Act of 6 November 2008 on Patients' Rights and Patients' Ombudsman, Journal of Laws of 2022, item 1876 as amended.

48 Karta praw osób z autyzmem, Uchwała Sejmu Rzeczypospolitej Polskiej z dnia 12 lipca 2013 r., [Charter of Rights of Persons with Autism, Resolution of the Sejm of the Republic of Poland of 12 July 2013], M.P. 2013, item 682, available at <https://isap.sejm.gov.pl/isap.nsf/DocDetails.xsp?id=WMP20130000682>, art. 10.

49 Ibidem.

50 Maciej Oksztulski, *Uprawnieni teoretycznie? Status prawny osób ze spektrum autyzmu na rynku pracy (w ujęciu krajowym, międzynarodowym i porównawczym)*, Presentation material: 13th International Congress Autism-Europe, Krakow 7–9.10.2022.

operate on the basis of the Act of 27 August 1997 on vocational and social rehabilitation and employment of disabled persons. The Regulation of the Minister of Labour and Social Policy of 17 July 2012 on occupational activity establishments is also in force.⁵¹ In accordance with the Act on Vocational and Social Rehabilitation and Employment of Persons with Disabilities (Article 29), 70% of the total number of people employed in this unit are persons with disabilities referred to work by the district labour offices: classified as having a significant degree of disability as well as classified as having a moderate disability who have been diagnosed with autism, mental retardation or mental illness, approved by the programme council of the Vocational Development Centre, justifying taking up employment and continuing vocational rehabilitation. However, the employment status of persons with moderate disabilities may not be more than 35% of all employees.

5.2 *Work Experiences of Persons on the Autism Spectrum from the Perspective of Vocational Development Centres in Practice (research February–March 2022)*

As part of research carried out with the support of the National Science Centre in the project „Uprawnieni teoretycznie? Status prawny osób ze spektrum autyzmu na rynku pracy (w ujęciu krajowym, międzynarodowym i porównawczym)” [Entitled theoretically? The legal status of people on the autism spectrum in the labour market (nationally, internationally and comparatively)] (Prelude 19, No. 2020/37/N/HS5/02224) investigated the employment practice of persons on the autism spectrum in several dimensions indicated. The aim of the research was to identify the main opportunities and barriers for the activation and professional work of people on the autism spectrum employed in Vocational Development Centres, the forms of support for professional activation that can benefit people with ASD employed in Vocational Development Centres, the opportunities and barriers in the implementation of the task of supporting professional work of people with ASD by Vocational Development Centres. The managers of Vocational Development Centres and people directly implementing activities supporting people with ASD were invited to participate in the research. The survey was conducted using an online survey questionnaire form and was prepared and planned in such a way that it could be

⁵¹ Rozporządzenie Ministra Pracy i Polityki Społecznej z dnia 17 lipca 2012 r. w sprawie zakładów aktywności zawodowej / Regulation of the Minister of Labour and Social Policy of 17 July 2012 on Vocational Development Centres, Dz.U. 2021 item 1934.

carried out by a non-verbal person.⁵² In the case of the Vocational Development Centre survey, the persons in charge of the institutions were invited to take the survey, and most of the questions were closed. On the other hand, in the case of surveys of people implementing activities supporting people with ASD, open-ended questions predominated in the interview questionnaire. According to the State Fund for the Rehabilitation of Persons with Disabilities data, there were 127 Vocational Development Centres operating in Poland in 2021.⁵³ According to the project's assumptions, one Vocational Development Centre from each province was supposed to participate in the survey, but in the end only 10 Vocational Development Centres that employ persons with autism spectrum disorder and 7 Vocational Development Centres employees implementing activities supporting persons with ASD participated, as well as 11 Vocational Development Centres from each province that do not employ persons with ASD. The survey sample is therefore not a representative sample in statistical terms, but it allows general trends to be indicated. Recruitment for the study took place by email and telephone (in the case of the telephone route, with the support of a support assistant).

Based on the recruitment, it can be assumed that in 2022 in Poland, people with autism spectrum disorder were employed by Vocational Development Centres in 8 voivodeships: out of all contacted Vocational Development Centres, 8 units in 8 voivodeships declared that they employ people with ASD. In order to determine the reasons for the diagnosed difficulties in employing people with ASD by Vocational Development Centres, the survey also included those units that do not employ autistic people, one from each province, of which 11 units responded to the invitation.

Among the main conclusions of the study, the operation of the Vocational Development Centres faces the following limitations:

1. Legal ones, first and foremost the ignorance of the legal requirements by Vocational Development Centres regarding their operation.
2. Organisational ones, such as differences in the level of work organisation of people with ASD and lack of vacancies.
3. Financial ones, in relation to low Vocational Development Centres funding ratios.
4. Social ones, such as learned helplessness of charges, problems with legal guardians, fear of employment, fear of charges and their families of losing their disability status, ritualism, formalism.

⁵² The project manager (Dr M. Oksztulski) is a non-verbal person on the autism spectrum with a severe disability.

⁵³ Zakłady Aktywności Zawodowej, Państwowy Fundusz Rehabilitacji Osób Niepełnosprawnych, <https://www.pfron.org.pl/institucje/placowki/zaz/>.

A top-down, institutional change is needed in which the activities of Vocational Development Centres are evaluated based on additional criteria.⁵⁴

6 Conclusions

International law, regional law (e.g. European Union law) and national legal orders treat people with disabilities equally, thereby homogenising the problem of disability, which is after all characterised by diversity. The legal basis for the status of autistic people must be sought in the general regulations of persons with disabilities.

At the international level, only a reliable and open exchange of experiences in the forums of international organisations can bring about a constructive consensus on the assumptions of the optimal status of persons on the autism spectrum. It seems that nowadays it is no longer a question of whether to help, only how to make it viable. Nowadays, European Union member states are developed enough to guarantee the right to work as much as fundamental rights and freedoms. At the same time, it cannot be expected that each will do this on its own – here there is a need for harmonization at the EU level based on international standards and the existing achievements of the European Union itself. Given that the employment of individuals with ASD is a challenge in other EU member states, coordinated legislative action by the European Commission is necessary to address this issue, which we recommend.

While some individuals on the autism spectrum exhibit high levels of vocational competence in open employment, low-functioning individuals typically require sheltered employment, often through access to facilities such as sheltered workshops. However, research indicates that such facilities in Poland often fail to operate as intended, resulting in a secondary form of discrimination against individuals with autism spectrum disorder compared to other individuals with disabilities. It seems, that this approach is determined primarily by economic factors. Full access to the labour market (open and sheltered) for persons on the autism spectrum in Poland requires appropriate legal solutions allowing funding and implementation of specific forms of support and improvements aimed at persons on the autism spectrum in the Polish labour market. Changing the approach can contribute to better implementation of the right to work for people with disabilities, in accordance with the general international standard.

54 *Doświadczenia w zakresie pracy zawodowej osób ze spektrum autyzmu z perspektywy Zakładów Aktywności Zawodowej. Raport z badań* [Work experience of people on the autism spectrum from the perspective of Vocational Activity Centres. Research report], April 2022.

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