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Neurodiversity and (Semantic) Space for Academic Inclusion of People on the Autism Spectrum

Abstract

There is a need to rethink functioning and the role of universities that implement inclusive education, understood as high-quality education for everybody, available at all levels of education because of the increasing number of neurodiverse people (with ADHD, autism, dyslexia and other disorders classified as neurodevelopmental).. The aim of our hermeneutical work is an attempt to identify opportunities and limitations on an empirical and theoretical level for creating conditions for the inclusion of students defined as neurodiversity. The research material consists of published own and other authors' studies, and the direction of exploration is determined by the following questions: Are there theoretical and empirical premises for the claim of full inclusion in the academic education of neurodiverse students? What are the research-related limitations that constitute a barrier to the academic inclusion of neurodifferent adolescents? The theoretical background of our work is the theories of social constructivism as defined by Alfred Schütz, Peter Berger and Thomas Luckmann. The research revealed

theoretical and empirical premises confirming the validity of the claim regarding the inclusion of neurodiverse students in academic education due to the intellectual potential of young people, their high self-awareness and the need to provide a growing number of neurodiverse students with conditions for maturing to self-determination in adult life. In Poland, but also in other European countries, the number of students diagnosed with an autism spectrum is not monitored at the national level. Single studies conducted in Poland indicate the similarity of the problems of this group of students with the results of explorations carried out in other countries, and include dropout during the first year of studies, difficulties in relationships with peers, a feeling of loneliness, and a low level of employment after graduation. A large number of people with autism spectrum does not study at all. One of the barriers may be the availability of higher education, which is related to the cultural and economic status. This aspect has not been taken into account in Polish and international research. There was also little dissemination of the idea of neurodiversity, which may be important for the perception of students with the **autism spectrum**.

Keywords: neurodiversity, autism, dyslexia, ADHD, student, university, monitoring the number of neurodiverse students, barriers

Introduction

The analysis presented in the article is the result of a meeting: the meeting of investigations by two authors, concerning the psychosocial aspects of functional disorders, including ADHD (Podgórska-Jachnik, 2019) and their emancipatory context (Podgórska-Jachnik, 2015) and concerning the issue of autism from the perspective of neurodiversity and the place for neurodiverse people in higher education (Cierzniewska, 2021) in the broader context of research on the academic community (Cierzniewska, 2011). This collaboration resulted in finding a common field of research focused on the application of the concept of neurodiversity in inclusive education, primarily at the level of higher education, but also at other levels and in other forms – in both epistemic and didactic aspects –

and support in general (authors' joint research project). A key joint discovery was the role of mental transformation in the perception of ADHD, autism, dyslexia, and of other individuals diagnosed with neurodevelopmental disorders, while creating inclusive openness of teachers in mainstream schools and universities by perceiving the potential of diversity (Cierzniewska, 2021). Nowadays, in Poland and around the world, implementing inclusive education – understood as high-quality education for everyone, available at every level of education – is an extremely important task, due to the need to rethink the functions and methods of operation of schools and universities. Some of the reflections have a more universal meaning, but the starting point and the most important area of reference in this article is university education. The aim of our hermeneutical work is to try to identify, on an empirical and theoretical level, opportunities for and limitations in creating conditions for inclusion for students labeled neurodiverse. The research material consists of published studies and the direction of exploration was determined by the following questions: Are there theoretical and empirical premises for full inclusion of neurodiverse students in the tertiary education? What are the research-related limitations that constitute a barrier to the academic inclusion of neurodifferent adolescents? The theoretical background of our work is the theory of social constructionism, as defined by Alfred Schütz or Peter Berger and Thomas Luckmann (Schütz, 2008; Berger & Luckmann, 2010).

Neurodiversity and the Paradigm Shift in the Perception of Students on the Autism Spectrum

Detailed research question: How does the neurodiversity paradigm change the semantic perspective on resources for research?

The term neurodiversity is not a new nosological unit. It is an attempt to turn away from the nosological approach in favor of a functional approach (Błeszyński, 2019, 2021), but at the same time it changes the language of description from negative, medical, paternalistic, pathologizing,

and ableistic (Bottema-Beutel et al., 2021) towards differentiation and the resources resulting from this differentiation, constructing the social world, and positioning people towards each other, as indicated by the theory of Schütz (2008) and Berger and Luckmann (2010). Neurodiversity is a form of neologism –an umbrellaconcept, that is, a collective descriptor, that defines neurodevelopmental diversity, which should be understood as an alternative to the concept sanctioned by medical science of a disorder, namely, neurodevelopmental disorder. Neurodiversity concerns people withautism spectrum disorder (ASD), Asperger’s syndrome (AS), dyslexia, dyspraxia, and attention deficit hyperactivity disorder (ADHD), which are not classified in terms of dysfunction, but by individual cognitive mechanisms (Molloy & Vasil, 2002, pp. 659–669). Doubts about this position concern the opposition of the concept of neurodiversity “tothe treatment of autism as a serious development disorder” (Gerc & Jurek, 2017, p. 189). Resistance to this concept is also met because of its failure to meet the classical canons of science:

It is not a falsifiable scientific theory that could create a framework for methodologically correct research. The objections to the concept are also related to the introduction of imprecise terminology, which obscures the generally accepted findings in the world of science. The concerns expressed by critics of this concept concern the issue of possible questioning and negation of the systemic solutions developed so far in the field of diagnosis, treatment, rehabilitation, and education of people with ASD. (Gerc&Jurek, 2017, p. 189)

Undoubtedly, the differences in the understanding of autism result from the theoretical provenance, and thus “neurobiological, socio-educational- and existential” paradigm (Gerc & Jurek, 2017, p. 197). Furthermore, Krzysztof Gerc and Marta Jurek stated that

psychology, characterizing states on the autism spectrum and relying on scientific premises, analyzes autism, starting primarily

from two distinguished approaches (most often from the first), heading towards a third. Autistic spectrum disorder is characterized as a neurodevelopmental disorder that implies serious, lifelong mental and social difficulties. (Gerc & Jurek, 2017, p. 197)

When reading their classification of positions on autism, it can be generalized that the first is embedded in the medical sciences and paradigms (experimental, with a normative methodological approach), while the second is social (interested in the social combination of individual dimensions of autism, including anthropological approaches which are methodologically normative and descriptive) and the third is rooted in the humanities (phenomenological-hermeneutical) including, for example, subjectivity, transcendentalism, and a methodologically descriptive approach. Their proposed division indicates the fulfillment of a specific cognitive interest (Habermas, 1983); therefore, the pursued scientific goal will be slightly different, and the scientific method results from the cognitive interests being satisfied (Czarnecka, 2016). The change/extension of the paradigmatic description of autism, the transition from a normative approach to a socio-cultural and humanistic approach, is indicated by the evolving positions of psychiatrists (Rymkiewicz, 2019) and strong arguments from Simon Baron-Cohen's an expert in autism. This is all the more so because this paradigmatic shift in thinking about autism does not eliminate differences within the spectrum, which can be described with the terms "dissimilarity," "disorder," "disability," and finally "disease." The first term refers to differences of a physical or mental nature that bring some potential for activity (e.g., a predisposition or lack thereof to play sports, compose music, systematize, or think analytically). The term "disorder" is used when there are symptoms causing the dysfunction and the cause is unknown. "Disease" is used when the disorder can be attributed to a specific causal mechanism. "Disability" refers to conditions in which a person experiences significant limitations in functioning that causes suffering in a specific environment (Baron-Cohen, 2019; 2021). Simon Baron-Cohen called the concept (not just a category) of neurodiversity "revolutionary" because "it offers a radically new view of the world – the view that there are many

varieties of the brain, and all of them occur naturally, instead of the old, inaccurate, binary division into normality and abnormality” (Baron-Cohen, 2021, p. 210). The strongest argument in favor of the concept of neurodiversity, in the broadest sense of the word, is the theory of “five types of brains” on the scale of empathy–systematization, according to which “each of us places ourselves somewhere on the bell curve” (Baron-Cohen, 2021, p. 74). The five brain types are examples of neurodiversity that are present in every classroom, student group, and workplace. “No variety is better or worse than the other – just different – and all have evolved to do well in different environments” (pp. 75–76). However, respecting the voice of criticism, it should be admitted that the idea of diversity cannot be used without reflection, depriving people who require temporary or permanent therapeutic interventions – especially those with a significantly lower level of functioning. Psychiatrists refer to systemic restrictions in this respect, stating that the use of the categories “disorder” and “disease” is a condition for starting treatment, but also allowing the term “state,” which is acceptable in the medical nomenclature (Rymkiewicz, 2019).

The category of neurodiversity in a narrow sense applies to people with high functioning on the autism spectrum (HFA), AS, ADHD, and dyslexia or dyspraxia, which in the case of students does not require additional arguments. They gain double chances of personal liberation: by attaining the highest standard of education and by therefore being able to see themselves only in terms of difference, not disorder or disability. It is worth noting that these opportunities complement and thus strengthen each other, which is an important justification for using the concept of neurodiversity in the context of creating space for the inclusion of people on the autism spectrum in academic education. It is also worth noting that identifying specific people using the concept of diversity also causes some lexical difficulties. While a group (e.g., a student group) can be neurodifferent, one cannot use “neurodifferent” to describe a singular person (one can differ from those who are not neurodifferent). Therefore, there are differentiations along the lines of “neurotypical person–neurotypical,” “norm–typical–abnormal,” etc. However, this is problematic when we inquire about the source and legitimization of the

alleged hidden norm. Contrary to their slightly different wording, these notions are not consistent with the assumptions of the neurodiversity paradigm, which is also described by the norm in atypical individuals. The literature also uses the term “exceptional,” or even “double-exceptional” (Wejner-Jaworska, 2019), which perfectly fulfills its role as a positive distinction, but for scientific purposes may offend with its euphemistic or overly common connotations. Renata Stefańska-Klar (2013) proposed a rather interesting term, “specifically different,” but the lack of the distinguishing feature “neuro” to refer directly to the concept of neurodiversity makes it less useful. In our opinion, it would be worth considering the term “neurodifferent” or “neuromuscular,” but that is not the main focus of this article. When speaking of a group of students on the autism spectrum, we continue to use the most common term, “neurodivergent students” (also confirming the fact that each group of people on the autism spectrum varies greatly between individuals).

To conclude this section, we will again turn to the theory of the five types of brains by Baron-Cohen, whose research showed that at least half of autistic people have an average or above-average IQ, and by analyzing a British study on 36,000 autists (the largest in the history of psychological research on autism) in which he and his team discovered that 66% of men and 50% of women have a so-called systematizing or hypersystematizing brain (Baron-Cohen, 2021, pp. 82–83). It is about intellectual dispositions to systematize and identify patterns, about people with interests in the field of exact sciences, music, architecture, analytical sciences (law, linguistics, economics, and philosophy), crafts, sports, nature, and cooking. But some of them also find themselves in fantastic works, writing dramas and detective stories with a complicated plot. This huge potential related to neurodiversity has already been noticed and valued by global business, and leading corporations have started to use these values to build a market advantage (Austin & Pisano, 2017), which opens up an opportunity for professional self-realization and the full use of the potential of people on the autism spectrum as well as those with ADHD, dyslexia etc.. More and more new guides for employers are being published in the English-language literature, joint conferences are being organized for people who

want to hire neuro-diversed people, there are even specialist employment agencies (e.g., Exceptional Individuals Ltd., 2020). These are not random decisions, but carefully thought-out and based on analysis – both psychological and economic strategies that combine the resources and interests of a potential neurodiverse employee with the interest and open attitude of a potential employer. Unfortunately, this phenomenon of managing diversity and differences is still relatively rare on the Polish labor market (e.g., Ernst & Young LLP).

Neurodiverse Persons (on the Autism Spectrum) Are Among Us – The Scale of the Phenomenon

Research question: In light of the data, what barriers can be identified in the inclusion of neurodifferent academic youth?

The first use of the category of neurodiversity by Judy Singer (an Australian autistic sociologist) in the 1990s concerned autistic people, but it currently includes those next to the autism spectrum and those with dyslexia, Tourette's syndrome, dyspraxia, and ADHD/ADD, with a tendency to include further disorders (Baron-Cohen, 2019; Mellifont, 2021). Detailed data on each of the above-mentioned states is not collected, so it is difficult to trace the changes in this respect. We know a bit more about the statistical increase in the number of people on the autism spectrum, including those with AS. In the 1980s, autism was diagnosed in 0.05% of the population; currently, global statistics suggest the possibility that autism has a prevalence of even 1% of the total population. A significantly higher number with a confirmed diagnosis was identified by American statistics from 2014, indicating that 1.47% of the population in the USA are people with autism and AS. Data from Great Britain reported the level of 1.1%. The authors of the NIK (Supreme Audit Office) report estimated that 0.6% of the population in the European Union have autism, or approximately five million people (Raport NIK, 2020).

In Poland, only on the basis of data from the Educational Information System (SIO) can we approximate the number of children and adolescents

diagnosed with autism, including AS, while the Electronic National System for Monitoring Adjudication of Disability allows us to determine how many people since 2010 have been awarded a certificate of disability or a degree of disability with the code 12-C – pervasive developmental disorders – which indicates a diagnosis of autism or AS. An analysis of data collected by the Supreme Audit Office shows that in the following years, between 2016 and 2019, the number of students increased by approximately 20% each year. The collected data show that “one in 115 students (0.87%) was diagnosed with autism or Asperger’s syndrome” (NIK Report, 2020). In subsequent nationwide studies commissioned by the Center for the Development of Education and the Ministry of Education and Science, prepared by Dorota Podgórska-Jachnik, the increase in the number of children with autism and AS was confirmed. Data collected at the end of 2019 and early 2020 indicated that there were 48,073 children in kindergartens and schools in total (Podgórska-Jachnik, 2021). From this it follows that there was a significantly higher increase than the 20% suggested by previous studies.

The audit of the Supreme Audit Office showed that

in the years 2016/2017–2018/2019, the majority of students with autism or Asperger’s syndrome continued their education in general secondary schools and technical secondary schools. The average results of graduation exams obtained in 2017–2019 by graduates with autism or Asperger’s syndrome did not differ significantly from ... other graduates. Slightly lower results ... were recorded only in relation to the exam in mathematics at the basic level, but in the extensions in mathematics and English the average result was progressively higher. (Podgórska-Jachnik, 2021, p. 42)

In Poland, there is no monitoring of students with autism and AS, and the Ministry of Education and Science (formerly the Ministry of Science and Higher Education) does not collect statistical data on the make-up of the population of people with disabilities, including students with

ASD (Podgórska-Jachnik, 2021. p. 43). For comparison, in the United Kingdom, data collected by the Student Affairs Office found that the percentage of students with social and communication disorders, including ASD, increased from 0.2% of the total in 2010–2011 to 0.9% in the years 2018–2019. The number of students with multiple disorders (including social, communication, sensory, medical, physical, and mental disorders) also increased during the study period from 30,955 (2%) to 44,490 (2.8%) (Lei & Russel, 2021). The Polish ministerial authorities' failure to monitor the number of neurodiverse students was surprising for us (especially in light of the NIK's post-audit guidelines), which made us to try to identify activities in this field in other European countries. In response to the submitted questions, Bureau of Research. Chancellery of The Sejm in Poland enquired about the mentioned issues at the analytical offices of the EU national parliaments through the European Center for Parliamentary Research and Documentation (ECPRD). It turned out that in most of the countries addressed, no institutional/departmental statistics are kept in this regard, which of course does not exclude the collection of data by other national institutions or organizations related to universities, as in the case of Finland. "According to the Student Health Survey, a research program conducted every four years by the Finnish Student Health Foundation (Ylioppilaidenterveydenhoitosäätiö) on Finnish students under 35, in 2016 Asperger's syndrome was diagnosed in 0.4% of students" (Inquiry No. 4848). Data collected by BAS (Bureau of Research. Chancellery of The Sejm in Poland) also revealed that

in Slovakia in 2020 there were 26 students with autism or other developmental disorders; in Hungary in the first semester of 2020–2021 there were 170 students with autism, and in the spring semester there were 153, which accounted for 0.06% of the total number of students. The other analyzed countries – Czechia, Estonia, Lithuania, Latvia, France, Spain, Portugal, Romania, and Slovenia – do not keep statistics on the number of students with autism and Asperger's syndrome (Inquiry No. 4848, n.d.).

Based on a statistical estimate, about 50% of the total number of people on the autism spectrum (Pisula, 2021; Baron-Cohen, 2021) are within the intellectual norm or above, of which 20% have outstanding talents (Attwood, 2013, p. 23). Thus, theoretically speaking, over a period of several years, about 20,000 students with such a diagnosis may start their education at universities. It should also be taken into account that some people are diagnosed at a later age (Hendrickx, 2018; Pisula, 2021; Simone, 2016). Many students who apply to the offices of rectors' plenipotentiaries for disabled people do not decide to disclose their diagnosis (such is their right) or there is no such diagnosis; they nevertheless receive help, which is guaranteed by the Law on Higher Education of 2018. Using the 1% rate, one of the three largest Polish universities – Adam Mickiewicz University in Poznań – estimates that it educates approximately 350 students with ASD, and employs approximately 50 such employees (Rutz, as cited in Majchrzak, 2021). According to our knowledge, nowhere are statistics collected or even needs related to the neurodiversity of academic workers identified, which may change in the near future, given the rapid development of the concept of neurodiversity and the self-adjudication movement of people with autism.

According to the information obtained by the Supreme Audit Office (from 12 universities and polytechnic universities), these institutions educated students and doctoral students with the autism spectrum disorder, who most often reported their diagnoses to the Office for Persons with Disabilities or to their lecturers and/or tutors or mentors; however, this pertains to those who have made themselves known. Researchers have identified the phenomenon of non-disclosure of diagnoses by neurodifferent people for fear of stigmatization or because they do not expect any reduced tuition or fees during their academic education (Opatowicz, 2021; Stefańska-Klar, 2010; Płatos, 2016). Returning to the NIK report, “in the 2018–2019 academic year, the universities which were surveyed had from two to 33 students with ASD. Despite the support received from 2016 to 2019, in half of the universities these students resigned from their studies or changed departments due to difficulties in social functioning” (Raport NIK p. 44). A similar phenomenon has been observed around the world

by many researchers (e.g., Cai & Richdale, 2016; Cullen, 2015; Moore-Gumora, 2014; Stefańska-Klar, 2010) and the most dropouts occur in the first year of university. On the other hand, we already have confirmation that neuronormative students have no problems with academic competences (Bekker et al., 2019). In light of the research, it can also be concluded that the greatest problems of neurodiverse people are those related to aspects of everyday life in the field of executive functions (Moore-Gumora, 2014; Gelbar et al., 2014). And it is this sphere and the degree of its efficiency that turned out to be a sensitive marker for predicting the level of neurodifferent students' academic success (Dijkhuis et al., 2021).

Summary and Conclusions

There is therefore a problem, not only with the rising number of potential students on the autism spectrum (we do not know the actual number), but also with creating conditions for education that would limit dropout rates at universities (Stefańska-Klar, 2010; Raport NIK). Our analysis of the high self-awareness identified in neurodifferent people indicates the possibility of them defining themselves as those with low self-confidence. (Cierzniewska, Podgórska-Jachnik, 2021). Experiencing this in the earlier stages of education could lead to the production of low self-esteem or could influence the strategies of coping with stress (Cierzniewska & Błachnio, 2021).

The growing number of neurodiverse students earning a high school diploma and entering university, theoretically speaking, should lead to a higher proportion of them among students. However, we do not see the living conditions, the previous educational experiences of young people, and the degree of their preparation for independent living away from home from this perspective. Only individual studies have taken into account variables such as place of residence and economic status, which – as one may assume – are important in the decision to continue education, often in a different city far away from one's place of residence. We know

little about the existential difficulties of neurodifferent adolescents, although sometimes such signals appear in the statements of self-advocates (Dec, 2020). These “down-to-earth” factors can nonetheless play a decisive role in educational decisions.

One factor that may prevent young adults from choosing to begin a university education may be their insufficient preparation in terms of functionality and coping independently, not only in the academic space but also taking care of themselves physically and mentally, as indicated by the studies discussed herein. An important factor for educational success turns out to be efficiency in the field of executive functions, which is difficult for neurodiverse students all over the world; the issue was also raised in Polish research. It should be emphasized that many studies confirm the importance of preparing young adults for independent life and there are already adaptation programs being carried out before starting university, which are still missing at Polish universities. Admittedly, in the last few years, Offices for Persons with Disabilities have significantly expanded their activities for the benefit of neurodiversity, but these issues deserve a separate study.

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