



PEOPLE WITH AUTISM IN THE LABOUR MARKET – SELECTED ISSUES

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Abstract. The number of people diagnosed with autism spectrum disorder is increasing every year. This problem does not only concern our country but has a global reach. Therefore, systems working for citizens, i.e. the social care system, education, professional activation, as well as the labour market, should be prepared to accept an increasing number of people with autism. Unfortunately, currently available statistics show the lack of coordination and effectiveness of aid activities, their limited scope, and the lack of interest in these people in the labour market.

OSOBY Z AUTYZMEM NA RYNKU PRACY – WYBRANE PROBLEMY

Słowa kluczowe: autyzm, spektrum autyzmu, rynek pracy

Streszczenie. Z roku na rok rośnie liczba osób, u których diagnozuje się spektrum autyzmu. Problem ten nie dotyczy tylko naszego kraju, ale ma zasięg globalny. Dlatego należy przygotować systemy pracujące na rzecz obywateli, tj. system opieki społecznej, edukacji, aktywizacji zawodowej, jak również rynek pracy do przyjmowania coraz większej liczby osób z autyzmem. Niestety, dostępne obecnie statystyki mówią o braku koordynacji i efektywności działań pomocowych, o niewielkim ich zasięgu czy o braku zainteresowania rynku pracy tymi osobami.

Introduction

It might seem that the issue of employment for individuals on the autism spectrum is rather niche. It seldom appears in public discourse. Unfortunately, statistics indicate that the number of people diagnosed with autism is significantly increasing each year. The World Health Organization reports that this disorder affects approximately 1% of the population. It is also estimated that autism affects 0.6% of the European Union's inhabitants, which amounts to about 5 million people (Torchała, 2023).

In Poland, such statistics are not maintained. Only the National Health Fund provides data on the number of issued diagnoses for autism spectrum disorder and Asperger's syndrome. In 2021, approximately 75,000 such diagnoses were issued, in 2020 about 63,000, and in 2019 – 57,000 diagnoses. These figures indicate an annual increase of about 20% in the issuance of so-called “positive” diagnoses. Also, “according to research conducted in recent years in various countries, autism and pervasive developmental disorders may become one of the most common causes of disability in children. About 40 years ago, the autism spectrum was diagnosed in merely 0.05% of the population, whereas current statistics show that it may be diagnosed in 1% of the population” (Torchała, 2023).

The increase in diagnosed cases of autism spectrum disorder has led to a growing interest in this condition (evidenced by actions such as the United Nations designating 2 April as World Autism Awareness Day). On the other hand, irresponsible opinions emerge about an “autism trend”, “overinterpreted research results”, or claims that “we are dealing with autism madness”. Such opinions not only harm the process of understanding this disorder but also directly affect the individuals concerned. Denying a “positive” diagnosis means a lack of rights to any type of disability benefits, access to specific forms of education, and a better understanding of the difficulties associated with stigmatization, which people on the spectrum experience in their daily lives.

The issue of diagnosing adults is a separate matter. Data on the number of cases among individuals in their forties and older with diagnosed autism in no way reflect reality. In Poland, this disorder began to be diagnosed only in the 1980s. According to estimated data, more than one-third of adults affected by this disorder have never been diagnosed. Adults with autism face numerous challenges in their personal lives (e.g., with self-understanding), as well as in social, family,

and professional contexts, and without a final diagnosis, it is very difficult for them to obtain the necessary support (Nowak, 2021).

This paper is primarily based on factual data. Its aim is to highlight the fact that socio-economic issues associated with autism do not occupy a marginal position among phenomena deregulating social life. On the contrary, the number of individuals and diagnoses of autism is increasing year by year. Therefore, there appears to be an urgent need to develop a support system that is coherent in all areas of functioning for individuals with autism, starting from access to rapid diagnosis, through the education system, and economic support, to the process of professional activation and achieving independence.

Socio-economic perception of autism

The social perception of autism should be considered in at least two dimensions – the dimension of perception and the dimension of understanding the nature of autism. This thesis can be supported by a study conducted by CE-BOS in 2021 (CEBOS, 2021). The results show, among other things, that 96% of the respondents have encountered the concept of autism, but their knowledge, as they admitted in the study, most often comes from television, including series (a prime example is the series *The Good Doctor* – 2017, creator: D. Shore); from the Internet, or from acquaintances. These are not reliable sources of information. It is mainly the type of knowledge that is formulated based on the superficial behaviours of people with autism. Its dissemination not only builds an erroneous image of autism but can also contribute to the perpetuation of stereotypes or prejudices associated with this disorder. Hence, the appeal of young people with autism, the protagonists of the film prepared on the occasion of World Autism Awareness Day titled *Tacy jak Wy [Just Like You]*, seems incredibly important. They express simple yet profoundly meaningful statements: “When you meet someone who is a bit different from you, you might get scared or feel uncomfortable. That’s okay. Everything that is new can be scary at first. But when you learn more, you will become familiar with it because you will have knowledge, and knowledge will help you understand. And understanding helps to accept”. Therefore, it is necessary to have knowledge about this disorder. This knowledge will mean that slightly “different” behaviours will only be information about an atypical way of perceiving the world, not a definition of a person with autism. As the film’s protagonists say about themselves, “I am a bit crazy”, “I have my weird hobbies”, “I spin various objects”, “I laugh inappropriately to situations”;

“I don’t like noise”, “It’s hard for me to say what I think”, “I don’t like changes”. These exemplary behaviours do not justify the terms “autistic person” or “autistic child” that appear quite often in publications. Such terms are extremely hurtful because the disorder affects only certain traits of a person, not all dimensions of their personality – especially since in recent years, scientific discourse has begun to use alternative terms, such as *conditions on the autism spectrum*, *development in the autism spectrum*.

Other data speak about society’s attitude towards people with autism: 41% of respondents believe that individuals with autism are capable of forming friendships; 43% hold the view that people with autism can work; 40% think that such individuals can live independently; 35% believe that people with autism are capable of starting a family, but 43% tend to disagree that such a child would cope in a public school. This may be reflected in data from the NIK (Supreme Audit Office) 2020 report, which indicates that the education of people with autism or Asperger’s syndrome most often ends at the primary school level (NIK, 2020). This is confirmed by information obtained from the Educational Information System, where we read that in 2018, there were 15,774 children with autism in preschool education institutions, 3,209 in primary schools, and 5,378 in secondary or vocational schools (NIK, 2020). The cited numbers testify to a very negative trend, namely the specific “disappearance” of individuals with autism from higher educational levels. Therefore, one must ask: What happens to these individuals? What is their social status? What are their chances in the labour market? Are they only condemned to live on state social benefits and family support? Do they spend their adult lives in social care institutions? It is worth mentioning that according to Eurostat data, the percentage of disabled people living in households with very low work intensity compared to the situation among able-bodied people in EU-27 countries in 2020 places Poland in the fourth, inglorious place (Główny Urząd Statystyczny, 2013). This statistic carries with it the spectre of isolating such individuals, depriving them of life and professional opportunities, condemning them to live on dramatically low social pensions or even, as the parents of these individuals claim, condemning them to staying in care homes or even psychiatric hospitals.

The aforementioned CEBOS studies also provoke the formulation of another thesis, that the assessment of the social functioning of an individual on the autism spectrum, given by respondents, is based more on popular opinions than on scientific foundations. Hence, it is inconsistent or even internally contradictory. On one hand, the prevailing view is that individuals with autism are capable

of working professionally, living independently, and forming social relationships. On the other hand, respondents approached the issue of the functioning of a child with autism in a “regular” school very cautiously.

It seems that this contradiction is based on the mistaken belief that autism is primarily a childhood condition from which one can “outgrow” to some extent, and that an adult on the spectrum functions significantly better than a child. This is one of the myths about individuals on the autism spectrum based on popular knowledge derived from the media. The authors of the National Autism Awareness Survey conducted in 2018 by the JiM Foundation argue that the knowledge of Poles about autism is very limited, which they are aware of. Autism appears to them as a much rarer phenomenon than it actually is. Autistic individuals are too often associated by Poles with extraordinary, exceptional abilities in a very narrow field, known as savant syndrome (JiM Foundation, 2018). An example is the character from the film *Rain Man* (1988, dir. B. Levinson) played by Dustin Hoffman, who portrayed a hero with Asperger’s syndrome. At the same time, autism is perceived by Poles as a phenomenon that places autistic individuals in a disadvantageous situation – related to suffering and ignorance on the part of the state. Most Poles also recognize the difficult situation of families who bear the burden of caring for autistic individuals.

Addressing the issue of individuals with autism from an economic perspective, it can be observed that experts’ opinions gravitate towards real data or even specific numbers. Here, one can refer to the 2022 report by the Polish Economic Institute, *Droga do otwarcia rynku pracy w Polsce dla osób autystycznych* [*The Path to Opening the Labour Market in Poland for Individuals with Autism*] (Kutwa, 2022). The authors proposed three scenarios regarding the employment of individuals with autism. In the first, optimistic scenario, it was assumed that individuals with autism would work 8 hours a day. In the second, moderate scenario, it was assumed that such individuals would work 6 hours a day. The third, pessimistic scenario assumed that individuals on the spectrum would work 4 hours a day. As a result of the calculations, it was determined that “An increase in the professional activity of individuals with autism could generate billions of PLN in contributions to the GDP. According to the assumptions of the moderate professional activation scenario for individuals on the autism spectrum, it would constitute an average annual GDP growth impulse of nearly 17 billion PLN. Over the years 2022-2050, the total contribution would reach 492.6 billion PLN – more than the amount of public spending in Poland for 2020. If individuals with autism are indeed capable of full-time employment,

the benefits would be even greater – the average annual contribution would reach nearly 23 billion PLN, meaning a GDP increase of nearly 7.8%; the impact on the Polish economy by 2050 would mean an enlargement of nearly 672 billion PLN” (Kutwa, 2022, p. 22). The increase in professional activity of individuals on the spectrum could lead to other positive effects, e.g., it may contribute to the improvement of public finance balance, the employment possibilities for their caregivers, and greater economic stability for families with an autistic member. In conclusion: “[...] the professional activation of individuals on the spectrum brings benefits not only on a micro-scale, i.e., for the individual and their close ones, but also on a macro-scale, contributing to an average GDP growth of Poland by 1.2%” (Kutwa, 2022, p. 4).

Furthermore, according to the authors of the discussed report, the benefits resulting from the employment of individuals with autism are five times greater than the costs of implementing their professional activation programs.

The data presented prove that individuals on the autism spectrum should not be viewed merely as a burden on the state budget, beneficiaries of social care, or objects of family concern. People with autism perceive the world in a different, atypical way. Understanding this will aid in their acceptance. Hence, the clearly emerging upward trends in positive diagnoses of this disorder suggest seeing individuals with autism as a significant human capital potential that should be utilized, for instance, in fields such as IT technology, accounting, data work, text editing, archiving, etc., but also as individuals performing monotonous, repetitive tasks at the workplace.

The paramount value of the professional activation of individuals on the autism spectrum is to provide them with an opportunity for “normal” functioning within the social environment, professional activity, and life independence.

People in the autism spectrum in the labour market

The necessity to address the issue of employment and work for individuals with autism is justified, among other reasons, by dramatic statistics. In the EU, the average employment rate for individuals with autism is around 10%, while in Poland it hovers around 2%. Both European and national figures speak of a vast number of people deprived of a basic right – the right to work.

There is a widespread stereotype of individuals with autism being seen as IT or mathematical geniuses, making careers in the IT industry or academia.

Unfortunately, for most individuals – even those described as high-functioning – the reality of entering the job market is much more brutal.

In 2020, the Supreme Audit Office presented an interesting report titled *Wsparcie osób z autyzmem i Zespołem Aspergera w przygotowaniu do samodzielnego życia* [*Support for Individuals with Autism and Asperger Syndrome in Preparing for Independent Living*]. The most general thesis from this report states that individuals on the spectrum are essentially invisible to the job market. While children and adolescents with autism are guaranteed conditions for learning and participating in education, individuals concluding this life stage cannot count on continued support and full access to effective vocational rehabilitation that would enable employment and independent living. This thesis can easily be confirmed by the job offers, or rather the lack thereof, in many District Labour Offices across the country. Job offers for individuals with autism are practically non-existent. According to the NIK report, “individuals with autism or Asperger syndrome rarely appear in the registries of job seekers. In 2018, only 78 such individuals were registered in district labour offices as unemployed or job-seeking, which could also result from the reluctance of labour offices to enter such detailed data about the unemployed [...] district labour offices do not have the possibility to provide these individuals with support tailored to their disabilities” (NIK, 2020, p. 17). Further, in the same report, it states: “data on the labour market already provided information on the situation of individuals with pervasive developmental disorders. The analysis of data contained in MRPiPS-07 reports showed that in 2016 and 2018, district labour offices registered respectively 63 and 78 disabled individuals with certified pervasive developmental disorders who had the status of unemployed (an increase of 24%) and respectively 19 and 38 individuals with this disability who were seeking work” (NIK, 2020, p. 52).

Considering the volume of data regarding individuals with a “positive” diagnosis and the fact that many adults with autism function outside the statistics of support institutions, it can be asserted that the figures provided by the Supreme Audit Office (NIK) indicate a negligible participation of individuals with autism and Asperger syndrome in the job market.

Institutions that have, as part of their statutory tasks, the provision of various supports to individuals on the spectrum for their professional and social activation include Vocational Activation Centres (Zakłady Aktywizacji Zawodowej – ZAZ) and Occupational Therapy Workshops (Warsztaty Terapii Zajęciowej – WTZ). Participation of individuals with disabilities in activities at WTZ or work in ZAZ represents a transitional phase, aimed at preparing them

for employment in either sheltered or open labour markets and enabling them to achieve full vocational and social rehabilitation. According to the NIK report, in 2018, about 34.5 thousand individuals participated in such forms of support – organized in 718 WTZ and 118 ZAZ (27.5 thousand in WTZ and 7 thousand in ZAZ). “Only in 22% of the workshops and 19% of the vocational activity centres in the voivodeships where the control was conducted, support covered individuals with the disability symbol 12-C as well as individuals diagnosed with autism or Asperger syndrome, based on other certificates (e.g., medical) and diagnoses (e.g., psychological)” (NIK, 2020, p. 52). The analysis of this part of the report also allows for the formulation of several theses.

Both Vocational Activation Centres (ZAZ) and Occupational Therapy Workshops (WTZ) generally show little interest in employing individuals with autism, despite the availability of additional funding for this purpose. According to the Supreme Audit Office control findings, these individuals constituted only 2% of the total number employed there. Furthermore, these institutions tend to admit participants or hire employees on a so-called trial period. Unfortunately, this form of employment does not favour the professional activation of individuals on the spectrum.

The regulations regarding the qualification of participants in ZAZ and WTZ are interpreted in various ways, leading to the application of different procedures in this area. Moreover, in half of the institutions, the “waiting lists” were not properly maintained. Vacancies in WTZ and ZAZ (especially specialized ones focusing mainly on supporting individuals with autism) were very rare because the duration of participants’ stay was long – most often 5 years or more.

The barriers to the proper functioning of Vocational Activation Centres or Occupational Therapy Workshops are not due to local or technical conditions – these are generally quite good. The most problematic issues are related to ensuring adequately prepared care and specialist staff. A significant problem is the lack of psychologists. Other specialists are only employed part-time or under civil law contracts. This leads to a relatively high staff turnover in these institutions, also due to low wages or professional burnout. Moreover, the labour market lacks individuals adequately prepared to work under the conditions of these institutions, and even if there are any, they are reluctant to undertake such difficult and demanding work for such low wages.

The program work in many institutions raises concerns. Indeed, individual rehabilitation programs or individual vocational and social rehabilitation programs are developed there, but, as the authors of the NIK report claim, they were not a good

tool for planning support because they were designed in a template manner with the assumption of unrealistic or unattainable goals. Furthermore, in more than half of the institutions (i.e., in five), the evaluation of these programs was carried out improperly, and the required modification of the provided support was not made.

The effectiveness of occupational therapy in Occupational Therapy Workshops (WTZ) is limited. The discussed report indicates that nearly all individuals with autism participating in occupational therapy in WTZ (80% of those surveyed) did not achieve the intended goals of vocational and social rehabilitation. There was also no justification found for these individuals to undertake further education, vocational training, internships, or professional employment. However, individuals with autism employed in Vocational Activation Centres (ZAZ) partially achieved the intended effects.

The management of ZAZ and WTZ is generally aware that a personalized approach to individuals with autism would yield better and more effective outcomes in their social and vocational rehabilitation. Unfortunately, the financial resources available do not give these institutions the opportunity to change their work with their charges.

The described issues are illustrated below.

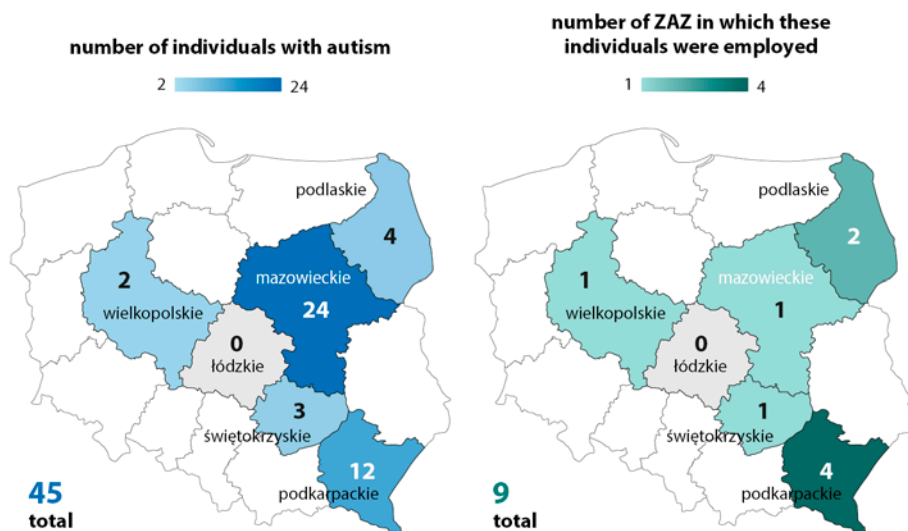


Figure 1. Number of ZAZ Employees with Autism Spectrum Disorder and Asperger's Syndrome in Selected Voivodeships in 2018.

Source: NIK. (2020). *Wsparcie osób z autyzmem i Zespołem Aspergera w przygotowaniu do samodzielnego funkcjonowania. Informacja o wynikach kontroli*, s. 65, <http://nik.gov.pl/plik/id,22196,rp,24863.pdf> (20.09.2023).

On one of the maps of Poland, the number of individuals with autism under the care of Vocational Activation Centres (ZAZ) was marked. In six controlled voivodeships, there were a total of 45 such individuals. The highest number was recorded in the Mazowieckie voivodeship – 24, while in the Łódzkie voivodeship, there were none. The second map illustrates the studied voivodeships where the employment of individuals with autism in ZAZ was confirmed. The total number of employed individuals was 9, with the most in the Podkarpackie voivodeship – 4 individuals, and in Łódzkie – 0.

These data illustrate the scale of the problem related to the employment of individuals with autism. Only 20% of individuals on the spectrum were employed in ZAZ in the area studied by NIK. What happens to individuals outside the scope of such support? Unfortunately, neither statistics nor analyses in this area are conducted.

The authors of the research paper titled “Ogólnopolski Spis Autyzmu (National Autism Census)” note that surveyed parents of autistic children have a very pessimistic vision of employment for even high-functioning individuals with autism or negative experiences associated with it. The prospect of their children finding work seems too distant or even impossible for parents (Płatos, 2017, p. 163).

In concluding the considerations on the spectrum of issues related to individuals with autism in the labour market, it should be emphasized that generally, employers in our country have limited knowledge about employing individuals with autism, despite the fact that doing so can bring them tangible benefits, such as exemption from payments to the State Fund for Rehabilitation of Disabled People (PEFRON), reimbursement of costs for adapting a workstation, and subsidies for salaries – monthly financial support for the wages of employees with a disability certificate.

Conclusions

It is widely known that the modern job market is characterized by instability, variability, and even capriciousness. However, certain tendencies can be discerned, such as a focus on social communication skills, a readiness for change, or a lack of employment stability. From this perspective, a vast number of individuals on the spectrum stand no chance of employment. No amount of courses on self-presentation or interview behaviour, nor social skills training, will change the behaviours of a person with autism, especially in social interactions or when

deviating from their known patterns of functioning. It is also unreasonable to expect employers to create special privileges or parities for individuals with autism or Asperger's syndrome. This is because they are a diverse group of people, just as in the neurotypical population. It is also not true that every individual with autism has hidden exceptional talents under the "cloak" of their disorder (the so-called "idiot savant"). Among them are highly functioning individuals as well as those requiring direct support in all aspects of daily living. So why are they treated according to uniform patterns of behaviour or measures of utility? It should also be noted that they are often offered training in professions long forgotten by the labour market. Speaking with the mother of 25-year-old Kuba, I heard: "He graduated from a special vocational school with a locksmith qualification. In a small-town environment, there are no job prospects in this profession. Kuba also no longer wants to attend Occupational Therapy Workshops because how many years can one spend learning to make paper flowers?" Another example is a group of students who, with great effort, passed their final exams but remained without any chance of further education in their local environment. This gives the impression that the system for preparing and activating individuals on the spectrum for professional and social participation only marginally considers the specificity of this disorder, its diversity, and the needs of people with autism. Considering the data, analyses, and information drawn from the literature presented above, several fundamental problems can be identified that the education system, health care, social assistance, and economy should address.

All individuals, regardless of the institutions they work for on behalf of people with autism, should have substantive knowledge about this disorder supported by pedagogical-psychological competencies. Common knowledge about autism and related myths are still prevalent in our society. As indicated in the NIK report, there is a lack of specialists, including psychologists, dealing with this disorder. Therefore, it is essential to provide further training on this disorder to all individuals who may encounter this issue in their work. This matter needs to be addressed proactively because, as it stands, teachers who have students with autism in their classes feel helpless in both their teaching and educational roles. They also do not receive support from parents, who tend to have an unwelcoming attitude towards the fact that there is another student with autism in their child's class. They more often perceive it through the lens of threat rather than benefit.

The second issue concerns the ability to diagnose individuals with autism and maintain substantive statistics in this area. This is essential for providing

these individuals with targeted support from educational institutions, assistance services, or those supporting vocational activation. As mentioned earlier, statistics in our country are based solely on National Health Fund (NFZ) data on the number of issued disability certificates. Neither in the education system nor in the social care system are separate data maintained. On what basis, then, are action plans prepared in these institutions? To what extent do they meet the specific needs of individuals with autism?

Another problem is the vocational education of individuals with autism, which most often takes place in vocational schools. Reality in this area shows that individuals with autism have a very limited choice of profiles and educational paths. They attend the schools that are available to them, not those for which they have predispositions or which match their interests or functional level. The previously mentioned statistic on job offers directed to them illustrate the scale of the problem. And yet, even individuals functioning at a medium level of independence can work in a stable environment, performing repetitive tasks, e.g., on a production line. Social and financial independence would be a tremendous achievement for them and a great relief for their families. Therefore, the education of individuals with autism should be more flexible, adapted to the capabilities of each student, but also to the possibilities and needs of the local environment. Individuals with autism rarely change their place of residence independently in search of work. Therefore, conditions should be created for them to function better in their place of life. These could be short courses or training programs that develop certain skills or competencies, focused on local needs. The vocational training of individuals on the spectrum cannot be based on rigid schemes under which training is most often provided for professions to which the school is adapted, not the students. It also cannot be a kind of “holding area” for young people with autism, serving only to keep them within the education system until a certain age specified by regulations.

Adult individuals with autism do not attract much public interest. They are somewhat “invisible,” confined to their homes under the care and maintenance of their families. Social environments tend to label them as failures, oddities, loners, or outsiders. However, their numbers are soon to be so significant that it will not be possible to keep them at home or place them in some facility indefinitely. Hence, the question arises: what offer will the education system, vocational activation, social care, or the community in which they operate present to this group? The indicators provided in the documents cited earlier are not projections; they are real.

It is important to highlight the issue of diagnosing adult women in our country for autism spectrum disorders. Research conducted by the JiM Foundation on *Autism in women in Poland* shows that only 303 women in 2021 benefited from services resulting from a “positive” diagnosis. These dramatic figures likely refer to the phenomenon described by British psychologist Anthony Attwood, known as the “lost girls”. For every girl diagnosed with Asperger’s syndrome, there are ten boys, although the researcher believes that the actual ratio is closer to 4:1 in favour of boys and men. For example, in Poland in 2021, 67,817 men and only 18,746 women were diagnosed (JiM Foundation, 2023).

In conclusion, it is worth recalling the position of historians who believe that Michelangelo, Isaac Newton, Wolfgang Amadeus Mozart, and Pablo Picasso were individuals functioning on the spectrum, yet their contribution to the development of civilization is invaluable.

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