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If I were a teacher...: Concepts of People on the Autism Spectrum About the Education System

Abstract

Assumptions: This article is part of a wider study on adults with autism. The main assumption of the series of studies is concerned with listening to and hearing the voices of those most affected – those with a diagnosis of autism. The material, which is based on the experiences of people with autism, allows us to present views on the role of the teacher – the creator of the educational space. Thus far, we have presented the experiences and comments of teachers and therapists; now we can listen to the voices of not only students and parents, but people with autism. The research problem was to present the educational experiences described by autistic people in a paper on pedeutology.¹ The aim of the study was to investigate the opinions on education held by people with autism.

Method. This study employed the netnographic method and involved a group of people with a diagnosis of autism who met online and agreed to participate.

Results. Reaching out to a large group made it possible to analyze their statements by ranking and creating meaning bundles.

¹ The research presented herein is part of a broader study to be published in a forthcoming book, titled *What People with Autism Tell Us About Education: Research Report*.

Conclusions. The first conclusion is that there is a difference in the approach to the teaching/learning process. This is due to symptoms that are specific to autism, as well as to the different educational and therapeutic approaches. The second conclusion is related to the use of punishment that, in addition to forbidden forms (such as physical punishment), often evolve into psychological and social punishment, such as isolation, marginalization, or a lack of interest. It seems to be equally important to draw attention to the ineffective attempts to impose recognized normative forms of functioning (often referred to as a violation), as well as treating these people as not fully intellectually capable, which is not a condition (intellectual disability can co-occur in a few cases [see Casanova et al., 2000]).

Keywords: education, adolescence, autism, netnography, teacher

In previous research and publications, I have dealt with the perception of autism spectrum disorder (ASD), trying to present it from the point of view of a person displaying the disorder (Błeszyński, 2020). Often, as professionals we are convinced of our knowledge of how to perceive and shape the world of others, including non-normative people. We know from experience that this is not always objective, but in fact most often deceptive. The problem of understanding the other person was addressed in philosophy by Husserl, Stein, Węgrzycki (1992), and many others (see Błeszyński, 2020, pp. 17–37). Therefore, it is necessary to understand the different perceptual states experienced by people with autism, for example. In this publication, I present a portion of the study with the aim of making a convincing case for the validity of phenomenological research, especially when we want to gain insight into a closed, separate (or separating), primarily different environment.

Research on people on the autism spectrum nowadays, requires attention to the new options for understanding autism. Thanks to the social, economic, and cultural (including religious) changes taking place, we are becoming a more open, inclusive society. This allows for extended analysis based on netnographic research, drawing on the students' own experiences and reflections on the educational process.

Description of the study group and the research method

The aim of the study was to investigate the opinions on education held by people with autism. The respondents were members of closed online forums which verified their diagnosis of autism. I have also cooperated with the foundations *Autism Team* from Łódź, *Prodeste* from Opole, and *Alpha* from Lublin, which bring together adults with an autism diagnosis and support their functioning in society. A total of 62 people from all across Poland took part in the study (34 women, 26 men, and two people who specified their gender as other). The respondents were aged between 14 and 47 years (average age: 28.3). Four students were in their final year of primary school, nine were in secondary school, and 14 were university students. Among the respondents, 33 had graduated from higher education in various fields (mostly the humanities and arts). The remaining two people did not indicate their education. These people mainly experienced mainstream education, at a time when many initiatives to support people with an autism diagnosis were emerging.

For this study, I used the netnographic interview method, which is based on the concept of Kozinets (2012). I have used it before in my research into people with autism and their functioning (Błeszynski, 2020, 2021; Garcia et al., 2009). In light of reviews and opinions, the material presented previously has served its purpose. Thanks to my cooperation with foundations and the community's interest in changing the perception of autism, it was possible to gather the relevant material. The study was conducted by means of an online survey in Polish which was placed on the Google Forms platform. The survey was distributed electronically and was available at a distributed URL to selected groups of people with a diagnosis of ASD.

The pilot study was conducted from November to December 2019, with the main study taking place in 2020 and 2021. The survey consisted of 20 closed-ended, multiple choice, open-ended, and evaluation questions, which were divided into four sections.

Closed questions:

- 1. General
- 2. Pertaining to education: preference of learning styles, forms of education, and therapy

Open questions:

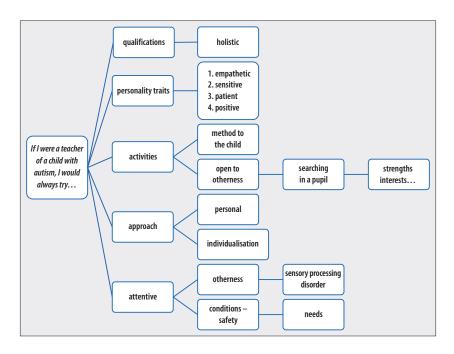
- 3. Respondents' vision of education and therapy
- 4. Evaluating institutional and non-institutional support

The research was voluntary and complete anonymity was ensured. The material was collected as part of research conducted at the Institute of Pedagogical Sciences of Nicolaus Copernicus University in Toruń and the Institute of Pedagogy of Cardinal Stefan Wyszyński University in Warsaw.

Cogitation on the state of the educator/teacher – "If I were a teacher..."

"If I were a teacher..." is a problematic statement that invites reflection, as it relates to internal beliefs stemming from one's experiences at school. These are our perceptions as well as our wishes, which stem from being a student, a parent of a student, or a teacher. These experiences are differentiated in time referring to historical and organizational conditions, for example, segregated education. Experiences are also related to the period of introduction of the integration and inclusion system, which can be described as a mixed and often heterogeneously introduced system, as can be seen in the different approaches to integration systems in European countries, from single team attempts to total integration, as for example in Scandinavia or Italy. It is these conscious or unconscious experiences that allow for a probabilistic, often wishful, idea of school. Imaginings do not always focus on idealized schools but often incorporate a rational view of the kind of school it should be by design, the kind of school one could aspire to. My research focuses primarily on analyzing the placement of the child with ASD in the education system. The first question that was asked of the respondents was "If I were a teacher of a child with autism, I would always try..." As mentioned above, the respondents formulated their suggestions based on their own child-hood experience of being a student with autism, which the education system considers to be a deviation from normal development, a disability, a disorder. According to respondents, the teacher should be guided by an adaptive, compensatory system geared toward the desired educational outcomes.

Figure 1. Statements of the respondents to the question "If I were a teacher of a child with autism, I would always try..."



The statements of the respondents can be divided into activities (duties) as one's status of an educator, personality traits that a teacher should have, and what they should pay more attention to in the case of children with ASD. At the forefront of the many qualities required of teachers is the

ability to sense the mental states of others – subjects, pupils, or the parents caring for them. The ability to adopt others' way of thinking includes looking at reality from their perspective. It is also the ability to imagine a mental perspective that belongs to another person: decentration.

This attitude is linked to patience and is based on personalization and individualism. Here, above all, a positive attitude is linked to sensitivity and to empathy. In principle, what is important above all else is not to cope, reduce, or lower the requirements, but to mobilize self-education and self-determination. The respondents highlighted conscious leadership and building on motivation towards self-development through guided, individual interpretation. Examples of this emerge from the concepts mentioned by the respondents (described according to gender [F – female, M – male, and O – other] and age in years): "understand the pupil" (F41); "listen to his/her needs, be patient" (M41); "look for strengths, follow special interests, learn from this child to see the world through his/her eyes" (F39); "understand what he/she feels" (O21); "respond to the child's needs, develop self-awareness" (F41); "look for teaching methods that suit the needs of the pupil" (M24); "find out what the sensory needs are in order to be able to emphasize some and minimize others" (F45).²

The actions taken should be based mainly on adapting the system to meet the needs and abilities of the pupil and learning about his/her resources and limitations in order to optimize the actions taken. However, such an approach is not a traditional system that focuses on mastering as much material as possible, but rather a progressive system that focuses on learning skills and using various sources. It is a search for opportunities for the student to expand their knowledge and to build skills based on their individual predispositions and aptitudes, which should be a determinant of his/her further development (for example: "try to build a positive relationship with him/her" (F43); "listen, support, and not interpret behavior,

² The quotes are translated from the original: "zrozumieć ucznia; wsłuchać się w jego potrzeby, być cierpliwy; szukała mocnych stron, podążała za szczególnymi zainteresowaniami, uczyła się od tego dziecka widzenia świata jego oczami; zrozumieć to co ono czuje; odpowiadać na potrzeby dziecka, rozwijać samoświadomość; szukać metod nauczania odpowiadających potrzebom ucznia; dowiedzieć się, jakie są potrzeby sensoryczne, żeby moc jedne wyeksponować, a inne zminimalizować."

give maximum security" (F19); "be alert to his/her needs and follow them, try to create a maximum comfortable learning environment" (F42).³

Working with a student with ASD is unique because of his/her different way of perceiving – which is based on perceptual systems (depending on the channels of experience) – and because of the need to perceive his/her condition (often referred to as *reading*). For example, the following concepts were mentioned by the respondents: "being sensitive to the student's needs, taking into account different emotional codes" (F41); "take into account the needs and the future of the child" (F18); "follow the needs of the pupil, help him/her to develop passions, adapt the forms of delivery of the material to his/her cognitive abilities; follow his/her step, interests and memorizing ability" (M22).4

These comments indicate positive attitudes toward behaviors found in students with ASD, often incorrectly formed approaches (due to our attitudes and negative experiences). This is often the result of the different emotional code of people with ASD, as well as the environment as it is perceived by pupils with ASD. This has a significant impact on their sense of security, and is due to the specific perception of sensations (e.g., thanks to people with ASD, quiet rooms have been created for neuralgic pupils). Some examples are "be aware of the child's needs and differences" (F35); "adapt the teaching method to the child (anyone, not just those with ASD)" (F36); "better understand emotions, feelings, and experiences (specifically sensory experiences, smell, hearing, etc.) in different situations" (O26).⁵

³ Original: "starała się budować z nim pozytywne relacje; słuchać, wspierać i nie interpretować zachowań, dać maksymalne poczucie bezpieczeństwa; być czujną na jego potrzeby i podążać za nimi, próbować stworzyć maksymalnie komfortowe warunki do nauki."

⁴ Original: "była uwrażliwiona na potrzeby ucznia, uwzględniałabym odmienne kody emocjonalne; brać pod uwagę potrzeby i przyszłość dziecka; podążać za potrzebami ucznia, pomagać rozwijać pasje, dostosowywać formy podawcze materiału do jego zdolności poznawczych; podążać jego krokiem, zainteresowaniami i możliwościami zapamiętywania."

⁵ Original: "zwracała uwagę na jego potrzeby i odmienność; dostosować metodę nauczania do dziecka (każdego, nie tylko tego z ASD); lepiej zrozumieć emocje, uczucia i doświadczenia (konkretnie doświadczenia zmysłów, węchu, słuchu etc.) w różnych sytuacjach."

The experience does not at all point to an ideal teacher, but to one who focuses primarily on the student, on his or her individual development, and on integrating him or her into the social system. Attention was drawn to the need for adaptation and inducement rather than simple assimilation. These are primarily actions taken by the teacher to enable the pupil to find his or her place within the peer group. The main objective is inclusion, understood here as being in the community, rather than transforming any of the parties (student or system). Creating optimal conditions adapted to the needs and possibilities are required to accept otherness, understand/comprehend and favoritism.

What we should avoid or abandon in our teaching work – "If I were a teacher of a child with autism, I would never..."

The experience of education also includes envisioning something that one would never want to experience in education. Pupils who deviate from the norm and are considered *non-standard* are especially affected; this applies to both gifted pupils and those with difficulties and disorders. In the case of autism, it is their abnormal social behavior that draws attention, as well as the range and depth of their interests. In such situations, the educational system needs to be modified and non-standard, specialized interventions sought.

After analyzing the material, I categorized the answers to the question "If I were a teacher of a child with autism, I would never..." according to the activities mentioned. In terms of the educators' behavior, the most frequently indicated negative impacts were verbal and physical violence. Despite assurances and the existence of recommendations and regulations, such as the *Charter of Rights for Persons with Autism* (Hague, 1992), the interviews very often included statements about violent behavior. These were arbitrarily regarded to be abnormal or forbidden, and in the case of people with ASD, to not produce the expected results (if not the opposite). These behaviors are often a sign of helplessness or professional burnout (Piętka, 2005) and should not be tolerated or allowed. The statements

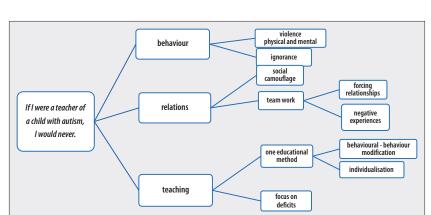


Figure 2. Statements of the respondents to the question "If I were a teacher of a child with autism, I would never..."

pointed to behaviors such as labelling, which aims to depreciate, or ignoring physical needs and emotions, which leads to a serious feeling of irrelevance or even applied exclusion. Here, mention was also made of judgement, often comparing against another person, as well as rushing and applying punishment.

The relationships developed in school have different dimensions. It is important to shape them, but not to force them, as doing so can create artificial relationships that result in violence or that ignore students with ASD. Negative conditioning within groups undermines self-esteem and well-being of students with ASD. As the respondents pointed out, the difficulty they face is teamwork, which – when imposed or treated as a limitation of autistic people – eventually becomes a hindering or prosocial action. The need for friends and peers for pupils with ASD is highly individualistic and often linked to self-determination.

The respondents pointed out the use of schematic approaches that indicate teachers' lack of understanding of their situation and social problems. For instance: "did not teach social masking" (M18); "did not expect me to learn in one particular way, even if this form of learning was convenient for me or worked well with other students" (M22); "I would not raise

my voice, would not impose being sociable, talking to peers. I wouldn't insist that everyone can and must have a girlfriend or friends. I know from personal experience that mobilizing in these areas in a 'Get on with it' way can make you depressed, discouraged, or irritated (M25).

When it comes to respondents' evaluations of education systems, a negative attitude was presented toward the behavioral influences that lie at the heart of the general (and special) education system. Behavior modification is mainly focused on change, on creating a different approach, and should focus on deficits (both partial and global) and predetermined change, such as striving to achieve a specific goal set by the teacher. Example statements from the respondents include "I would not use violence" (F42); "I would not judge, I would not label" (F39); "I would not force with behavioral methods, shout, ignore his/her needs, messages, or use violence" (M42); "certainly corporal punishment, raising one's voice is not an option, neither is holding/restraining in other ways. I also find it unacceptable to ridicule and treat a child like a half-wit, because if they have a diagnosis of autism they probably understand less than their peers, so they require adjustments, as does a child with NI/strong learning difficulties themselves, not just a comfortable environment at work. In my opinion, it is also bad to be forced to participate in PE lessons. The lights shining in your eyes or the classes that were embarrassing for me, e.g., movement and dance classes, which I remember as the worst, and I was lucky not to take part in those despite the threat of getting the lowest grade for standing there like a pole" (F40).6

⁶ Original: "nie stosowałabym przemocy; nie oceniała bym, nie etykietowała; wymuszała metodami behawioralnymi, krzyczała, ignorowała jego potrzeby, komunikaty, stosowała przemocy; na pewno kary cielesne, podnoszenie głosu nie wchodzi w grę, podobnie jak przytrzymywanie/krępowanie w inny sposób. Niedopuszczalne jest również dla mnie ośmieszanie oraz traktowania dziecka jak półgłówka, bo skoro ma diagnozę autyzmu to pewnie mniej od kolegów rozumie, więc wymaga dostosowań jak dla dziecka z NI/mocnymi problemami z nauką samymi w sobie, a nie jedynie komfortowego środowiska w pracy. Złe jest też moim zdaniem zmuszanie do lekcji WF, walące po oczach lampy czy krępujące dla mnie zajęcia np. ruchowo-taneczne wspominam najgorzej, a w tych drugich udawało mi się na szczęście nie uczestniczyć mimo zagrożenia jedynkami za stanie jak słup."

The issue of social masking, as the striving to become (as adaptation) more like one's peers, one's social environment – as mentioned by Liane Holliday Willey (2015) – was also addressed. This is a model of social utilitarianism, rather than a search for the individual qualities of the subjects, which is also a problem of unjustified extreme individualization, which makes it inherently impossible to adapt to the needs of the wider society. My previous research (Bleszynski, 2020) has already identified misplaced generalizations about students with autism. Some of the perceived generalizations are that students with autism are primarily interested in scientific subjects or that autism causes secondary intellectual disability or developmental delay. This assumption somehow forces the system to adequately adapt the curriculum in the education system toward people with autism: "she did not force him to do group work" (F35); "did not make him do something he already knew how to do" (F26); "she did not force the child to socialize, shout, ridicule, or allow peer violence" (F28).

Summary

In conclusion, I would like to highlight the fact that the education of people with autism is mainly viewed from the perspective of teachers and the parents of such students. Many publications present ways to organize forward-looking models, such as May et al. (2020, pp. 331–339). Also, the work of Bolourian et al. (2021) is interesting; it outlines teachers' perceptions of autism and demonstrates opportunities for inclusive interactions and the formation of social relationships. McDougal, Riby, and Hanley (2020) outlined the problems faced by teachers teaching in classrooms with children with autism; a similar analysis was presented by Sciutto et al. (1999). Also, it seems important to address the perception among teachers that autism is a disorder that hampers the educational

Original: "Nie zmuszała go do pracy grupowej i nie kazała robić czegoś, co już umie; Nie zmuszał na siłę do pracy zespołowej; nie zmuszała dziecka do kontaktów społecznych, nie krzyczała, nie ośmieszała, nie zezwalała na przemoc rówieśniczą."

process, as mentioned by Arif et al. These observations are consistent with the experience of Polish teachers, as described in research conducted by Antonik (2015) or Woźniak (2018), who point out the difficulties in education. However, the mainstream approach is individualized guidance. This system is based primarily on incentives and the use of punishments and rewards (for example, in the form of applied assessment). In the case of pupils on the autism spectrum, one of the most effective methods is based on behavioral interactions, which was adopted in the 1990s (Schopler et al., 2002). At the time, alternative forms of education and therapy for pupils with autism were emerging (e.g., the Option Method). This is a response to a non-directive system of pedagogical influence. The statements of the respondents presented herein allow us to direct our visions of education away from differentiation and separation, mainly toward an inclusive education in which forms of coercion, imposition, and punishment cannot be used. This approach, indicating the importance and necessity of moving from segregated education to inclusive education was presented by Rebecca Wood (2019), who confirmed the approach with empirical research. According to the positive vision, school should be individually tailored to the needs and abilities of the pupils, adapting optimally without abandoning educational requirements. This is first and foremost enabling and following the student with the reguirements. The respondents indicated that school cannot be understood as an imposed and enforced education and upbringing model, and that it is important to allow the student to influence this educational program. It should be noted that people on the autism spectrum often drew attention to the downplaying, leniency, and abandonment of interventions on the grounds of autism, which they considered to be inappropriate or even derogatory. Particularly from their adult perspective, they were critical of the possibility of being ignored because of their diagnosis. Autism, from their point of view, is not a limitation, but a different perspective on knowledge and the surrounding reality, which often does not conform to commonly accepted norms. This results in frequent misunderstandings and negative attitudes toward people with autism, who are described as difficult to live with, having limited perceptual capacities (often referred to as handicapped), and not conforming to the assumptions of the education system and the conventions accepted in society.

The current state of knowledge, as well as the development of research and analytical techniques, should compel us to continue to gain insight into the experiences of the people described, rather than limiting ourselves to our own experiences. This shifts the focus onto the subject, a student with ASD in the school system, and moves away from the beaten track of education in favor of listening and searching for alternative, innovative solutions – starting with the essence of inclusion. To achieve an open and searching society, it is important to respect and enable those who hitherto have been defined as *Others*. It is a move away from the primacy of knowledge and its transmission, toward exploration and formation.

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