

# CHANGE IN APPROACH TO PROBLEM OF AUTISM SPECTRUM DISORDERS: TOWARDS THE HUMANISTIC AND PERSONALISTIC PERSPECTIVE OF UNDERSTANDING THE PERSON

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**Abstract:** Understanding a whole person is said to be the most difficult challenge of social, humanistic, medical and other sciences. It especially concerns the issue of understanding unique individuals, those perceived as different, non-standard (in any meaning of this word), uncommunicative or strange way by the majority of people. To understand these individuals, one can describe them, define them or penetrate their problems which could be effective only via inclusion. In case of individuals with ASD, due to remarkable progress in recent research, which evolved from exclusion, determining patterns and labelling towards an approach of finding common features and approaching individuals with ASD in a holistic way. A number of notable people with ASD are known in history. They fought for their rights and dignity. These people highlighted how important social development is and proved the working power of inclusion. Nowadays, we should listen to this group of citizens and research subjects so commonly excluded from society. There is a plethora of opportunities to learn about autism and try to understand ASD individuals who can teach researchers about their problems.

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## INTRODUCTION

Understanding a whole person is said to be the most difficult challenge of social, humanistic, medical and other sciences. It especially concerns the issue of understanding unique individuals, those perceived as different, non-standard (in any meaning of this word), uncommunicative or strange way by the majority of people. To understand these individuals, one can describe them, define them or penetrate their problems which could be effective only via inclusion. In case of individuals with ASD, due to remarkable progress in recent research, which evolved from exclusion, determining patterns and labelling towards an approach of finding common features and approaching individuals with ASD in a holistic way.

A number of notable people with ASD are known in history. They fought for their rights and dignity. These people highlighted how important social development is and proved the working power of inclusion. Nowadays, we should listen to this group of citizens and research subjects so commonly excluded from society. There is a plethora of opportunities to learn about autism and try to understand ASD individuals who can teach researchers about their problems. The author would like to express his gratitude for Professor J. Kossewska from Pedagogical University of Cracow for organizing an excellent conference „Focus on Autism” (27-29.0.2018) during which, the author could present the results of his research on autistic subjects and share their outlook for the world.

## GETTING TO KNOW ANOTHER PERSON

How to understand the other person? This is a basic question that the humanity has been struggling with from the very beginning. In the biological approach, scientists can sum up the whole process as perception or noticing. It is the activity of systems that have the task of receiving, processing and storing information from the environment - they reproduce and use it according to the needs and capabilities of an individual. The basis of perception are senses, on which humans create their reference to the surrounding world, including other human beings.

In psychology attention is paid to perception as a cognitive ability that is significantly determined by our psychophysical abilities. However, the essence of cognition is the search for the possibility of crossing the boundaries of the psycho-physical reflection of the image in philosophy. Edmund Husserl believes that the ultimate phenomenological subject, who is not subject to any exclusion, is the subject of all intellectual and phenomenological research, a pure self (Husserl 1974, 247). It is only the cognition of the other person that can be based on empathy (*Einfühlung*) as indirect presence (Husserl 1974, 281).

Stein (1917) introduced the humanistic aspect of the discussion, noting the position of the human in community, not only treating it as a separate individual. Thus, empathy, it becomes a kind of experience of being in space and time with material processes and mental experiences (Stein 1917, 68). Expanding the field of experience, deepening the element of understanding, experiencing same motion allow one to penetrate into the acts of another human being, his realm of being, his personal spirituality. Scheler (1972; 1980), created a theory of cognition, which is now the basis for cognition in the humanities. Man, as a social being, perceives another man as belonging to a specific sphere of being defined as "the world of You" (*Duwelt*). Węgrzecki notes that in a living community the other person is thoroughly analyzed through direct observation and co-experience. In contrast, for society, the separation of the "survival" and "bodily word movement" is a variable in other people (Węgrzecki 1992, 50).

According to Węgrzecki, whose theory is the basis for researchers seeking the optimal possibilities of knowing the other person, being becomes a being that continues to define and self-determine, but is also cognitively defined also by sources that are outside it. The results of determining the existence of a human being by someone else can coincide with the results of self-determination (Węgrzecki 1972, 127). This self-knowledge is connected with the cognition of another human being, it becomes a kind of background that marks and cuts the existence of a man from the environment. It can be stated that it is in other people's manifestations that a man finds the reflection of himself (Węgrzecki, 1972, 129). It is thanks to contact with another person that the whole process of self-discovery takes place. So a

man being a scientist, interested in learning about others, shapes himself. This openness to others becomes an important element of self-creation. It is the dimension of co-existence and co-participation that becomes important and irreplaceable in this cognitive dimension. As A. Węgrzecki wrote, thanks to such experience, it is possible to gain an insight into the specific dimension of human existence, which makes the other human something unique (Węgrzecki 1972, 132).

The transition from empathy, social influence factor, cognition based on our own experience, to the forming of another human being becomes an important model of looking at research that gives the second person not only the character or subject of the subject, but also affects a different view of understanding - as an auto - empathy, in the eidetic<sup>1</sup> and phenomenological view of Husserl's cognition of man. This approach should characterize the new view of autism / autism spectrum disorders that deviate from assessment, classification or labelling.

This approach should take into account:

1. opportunities to conduct research among people who can present their experiences in a partner way;
2. deviating from classifying and grading for placement, which is undoubtedly enabled by the new DSM 5 classification (introducing descriptive characteristics of CTS grades);
3. developing at the appropriate level of social awareness and inclusion culture;
4. the use of individualized forms and methods (without direct contact) of obtaining information/ research material.

#### METHODOLOGICAL ASSUMPTIONS

An important element of conducting research is establishing cooperation (or, as M. Hessen mentions, the relationship he calls 'love'). In connection with the above, the author decided to use modern techniques of communication, which allow indirect engagement in the research cycle, and in the case of people with autism spectrum

<sup>1</sup> Eidetics [Greek eidētikós 'ideal', 'formal' < eídos 'picture', 'character', 'pattern'], in phenomenology it means knowledge about the important, introduced by E. Husserl: phenomenology according to him has eidetic character i.e. in the process of constant changes of content of some performance searches for constant elements. It does not focus

disorders, do not cause cognitive and emotional limitations. I have written more about it, in the description of eye contact and compensation mechanisms, conscious, not always understood by the environment, eliminating mechanisms limiting communication. The researcher experiences discomfort when he makes eye contact, the world around is blocked. The author can only process the huge pain and discomfort that comes to his mind. This pain passes when he looks away; he listens and concentrates better when there is no eye contact; np looks at the forehead, between the eyes of the respondent, to hide his confusion (Błęszyński 2018)

To limit direct contact the author decided to use a questionnaire which consisted of 14 points. The document was placed on the Moodle platform, with general access, providing information to centers working with youth and adults with ASD. The interview consisted of introductory questions (without personal data), information about sensory perception and references to the perception of autism by the respondents. Apart from general questions, they were all open, allowing an unlimited form of expression. The research was not aimed at obtaining categorized answers, the aim was to get to know as much as possible about the world as perceived by people with autism. The author made a preliminary analysis in cooperation with Gumińska, MA, PhD candidate, who studies the quality of life of adults with autism (a dissertation being prepared). The Center for Early Intervention in Giżycko and the Foundation Farma Życia - Community of Hope in Więckowice, Poland answered the call for help in conducting the research. It should be noted that the material presented is a part of the research that the author plans to publish as a whole.

#### FINDINGS

15 individuals (8 females and 7 males), aged from 13 to 45 years (6 people: 10-19 years, 4 persons age 20-29, and 5 over 30 years old) took part in the study. It is a large age range, as well as awareness

on the phenomenon in specific environment but pays attention to its essence. Husserl used to use a triangle symbol, whose geometric definition is independent from the length of its sides. (<https://encyklopedia.pwn.pl/haslo/ejdetyka;3896920.html>; Accessed 7<sup>th</sup> September 2018).

of different social interactions on the ongoing changes (since 1970, when education was merely a system of segregation).

#### SELF-AWARENESS OF ASD

After analysing the obtained answers, it can be stated that in the case of self-awareness of the disorder and self-reflection over the role of the disorder in achievements, a very different information has been obtained. Negative connotations attributed to autism prevailed. Most often it is presented as a disease, dysfunction on social functions, interpersonal contacts, difficulty in social functioning. It can also be interpreted that autism is a constraint, essentially permanent and impossible to cross - from the respondent's side, for example, like a cage that is difficult to leave. It is also showing the otherness (as one of respondents states), or as another respondent states - something unusual, deviating from the norm, which does not necessarily have only a negative aspect. There are also statements that show the difficulty in presenting a multidimensional character - the respondent finds it difficult to say whether he or she is a good example for people and for the country and life. This polarization is mainly due to the difference in the age of respondents.

Autism becomes a hindering element that creates a limiting barrier. This barrier delimits autistic world of the respondents, but does not necessarily mean that it delimits the world from them. It is the awareness of the difficulties inherent in them - what has been called by this external world (specialized terms - disease, dysfunctions), which can only give meaning, but not necessarily the essence of the problem - as an element inherent in them, and therefore demanding impact:

- of adaptive, external environment;
- of internal self-reflection, on what is not cooperative;
- as modifications, adaptation, accommodating (more psychological adaptation, as modification and improvement under the influence of acquired experience).

#### THE INTENTION OF MAKING CHANGES IN YOUR LIFE – WHAT WOULD YOU CHANGE IN YOUR LIFE?

The most significant seem to be proposals, or even a call to make changes in relation to the educational

system in the scope of applied care and educational methods. They mainly result from the imperfections of the education and care system, despite numerous changes and system modifications. This is an indication of difficult-to-accept impacts on bodily harm (e.g., do not beat me) or a sense of security, e.g. by imposing eye contact.

In relation to the respondents themselves, prosocial features would be shaped, but with preservation of their own predispositions and character traits. This may be the result of commonly used behavior modification techniques of a directive nature as well as a school system aimed at compliance. People with ASD are aware of having their own personality, their predispositions, often difficult to modify and causing a lack of social understanding and acceptance. This awareness increases with the acquisition of the ability to distance oneself and the feeling of social aspiration.

Respondents indicate, for example, the use of their strengths, which they themselves see, for example, making a sports carrier in running, winning medals and cups; working and achieving more; going to the Paralympics in the future, that the authors look at someone when they talk to them, because it's unpleasant when you do not look at someone. These indications also refer to changes e.g. in the environment in which I operate; I would change the human mentality. In younger subjects, there are answers: nothing; I do not know; the proposals also apply to themselves, e.g. it would be very nice if I was more confident and able to communicate with other people e.g. in the environment in which I operate; I would change the human mentality.

The essence of the above-mentioned behaviours is the striving to be in interaction, social bond. The respondents are aware of the pursuit of the goal as well as the goal itself, but it seems that commonly used methods of stimulation in the education process are not adequate for people with ASD. Difficulties result primarily from the lack of commonly accepted stimulus models, such as declarativeness (Baron-Cohen 1989), initiation of interaction, interaction, cooperation, reinforcement (Swinkels et al. 2006, Mundy, Sullivan and Mastergeorge 2009; Demurie et al. 2011). There was also an aspect of loneliness, isolation coinciding with research on well-functioning

students with ASD compared to properly developing peers, who more often give loneliness in their answers (Bauminger, Kasari 2000, Bauminger et al. 2003, 2004).

#### AWARENESS OF MODIFYING ONE'S BEHAVIOUR

The preference of states, which are generally considered and perceived as pleasant, ensuring an appropriate level of well-being is an important element of the respondents' statements. Scooping distance, emotionless relation to the reality of the person with ASD function - both with regard to oneself (e.g. Less and less with age, another way of looking at people), as well as the environment should be mentioned at this point. Respondents point to their passions - which are often limited to the field of interest (e.g. a big knowledge about cars and that I have a large collection of brochures / albums related to cars and I love to drive). They also present the form of their behavior, e.g. I read in pictures, I like to count for hours; I have an imagination (I imagine different stories). There are also answers such as, for example, I have no idea.

Self-reflection concerns strengthening the skills of interpersonal contacts as well as building one's own authority and self-awareness. With age, it is possible to find more features that have the character of reliable participation, as a result of the experience of seeking to share social interactions. Attachment styles are an organizational pattern for shaping social interactions at particular stages of development. As shown in the studies, attachment styles are most often safe, but may be deformed under unfavourable conditions (Ainsworth at all, 1978). Awareness of mutual modification - referring to society and respondents - is equally important. It is a necessity to reach a consensus, undoubtedly a socially desirable attitude, but one that can be achieved in pro-social development - this is an important aspect of inclusive education, contrary to the segregation and isolation education system. It should be noted that the acquisition of social skills by persons with ASD is atypical and heterogeneous due to the occurrence of various, different and time-bound disturbances that are significant and often comorbid (Rutgers et al 2004; Pisula Pisula 2000; Naber et al. 2007). These studies also confirm observations made during school activities, especially related to the development of free time. Interactions - students

with ASD, if at all they entered them, were mostly unsuccessful and characterized by the inability of initiating and responding to interactions with peers (Hauck et al 1995; Stone and Caro-Martinez 1990; Travis and Sigman 1998).

#### DISTINGUISHES YOU FROM THE OTHER PEOPLE?

Older and more experienced respondents point to vanishing differences, as adapting to social requirements, as well as increasing tolerance of society. An important aspect of the respondents' attitude to the surrounding reality is their age. As the oldest respondent notices, with increasing age, there is an increasing assimilation (what distinguishes you from others? - with age? less and less). This is undoubtedly the result of tolerance (each of us is different) and integration into and with society (observing people), as well as the increasing awareness and acceptance of people with ASD. Important becomes scooping distance, emotionless relation to the reality of the person with ASD function - both with regard to oneself (e.g. Less and less with age, another way of looking at people), as well as the environment. Respondents pointed to the different characteristics of each of them in lifestyle, preferred forms of activity, interest (fixation), etc. Younger ones answered about their narrow interests and attempts to channel their experience by people supporting their development.

It should be emphasized that the respondents are aware of their otherness, the requirements relating to the organization of social support, which ultimately lead to improvement in their socialization and functioning in the environment. However, it is not attributed to third parties that discipline and shape their behavior (support assistance). Many of the presented interests, often taking the form of fixation, are transient, evolving and constitute the basis for further exploration of the environment (Prizant, Fields-Meyer 2017). Many autobiographical publications indicate the legitimacy of the emerging narrow interests and the possibilities of developing them (Grandin 2011; Willey 2018).

#### HOW YOUR ASD IS BOTHERING YOU?

In the responses given, one statement actually appears. The respondents mention difficulties in

social contacts as a problem. Perception of otherness may be an indication of alienation from society. Among the statements dominate those showing awareness of the limitations of interaction (e.g. in easy establishing contacts, it hinders my contacts with people, and making new acquaintances, I practically do not acquire friends), as well as entering social structures (e.g. in developing social interaction) and also defining such problems as a trait (permanently, it in no way bothers me).

This restriction sometimes hinders the creation and maintenance of social contacts. Social contacts are the base on which the social functions of active action and participation are shaped. It can be pointed out here that acting as an activity is an essential element in the proper building of social relations. An action that is often unintelligible is often socially incomprehensible, unacceptable. This awareness, but also the intentionality of looking for friends, interacting are the elements that both parties face. Approaching this interaction in a skillful manner must often facilitate reaching a compromise to find a way to this interaction. The search for this interaction, starting with Grodzka (2010), is shown as taming by watching and imitating Kaufman (1994), or the conditioning strategy of Lovaas (1993).

The problem in social contacts typical of respondents is the difficulty in establishing and maintaining eye contact. The conducted research indicated that there are difficulties in visual contact during direct contact and are characterized by a short period of attention on the face (Klin et al., 2002; Nakano et al. 2010), which may be related to preferred objects - mostly statistical (Sasson et al. 2008; 2011). In dealing with children with autism, the problem of sound perception is often encountered (Klin 1991; Kuhl et al. 2005), which, as mentioned, is of a social nature, which often causes that verbal communication is not used in social communication (often referred to as being used inadequately). Children with ASD respond to non-verbal stimuli, e.g. non-social stimuli (Ceponiene et al. 2003; Gervais et al. 2004). Lack or impediments in the development of social contacts using the sense of sight and hearing may be one of the symptoms of autism, which can also be defined as the risk of autism incidence (Elsabbagh et al. 2012; Pierce et al. 2011, Allison et al. 2008).

## CONCLUSION AND IMPLICATION

Preliminary results from the research indicate that consciousness (Lniu et al. 2010), as well as the self-awareness of people with ASD is not only an important element of research, but could also help in the creation of a map of the disorder itself. Recent research shows a broader understanding of perception and specific occurrences may result from many factors. As described by Sivaratnam and others (2015) these factors can be traced to early development of brain structures in prenatal, natal and postnatal periods, or as indicated by the latest classification of DSM 5 in early childhood; they rise from difficulties resulting from the ability to perform executive functioning; they are disturbances of the neuroendocrine process; they can appear as a result of an abnormal perception of additional information. This approach presented by the team of Sivaratnam, Louise, Newman, Tonge, Rinehart (2015) indicates a much wider range of necessary research based on the analysis of neurobiological, neuroendocrine and neurocognitive processes that underlie the processing of information coming from environment. However, it is important not only to analyze the neurofunctional materials, but to research their symbiosis with information obtained directly from the interested persons.

Summing up, the presented material, the author wishes to draw attention to the personalistic review of the collected material, the subjectivity, and thus the necessity to change the options of this ASD study. We encounter several important conditions, and one of the more and more distinctive aspects is the cultural reception and description of autism (e.g. Gumińska and Smiley 2015). It shows a multidimensional context - not only biological, but also social and cultural. In spite of the emerging studies on the perception of autism in different countries and cultures, there is still no uniform presentation of the problem. This is confirmed by the multinational team (Matson et al. 2011, 1601-1603), indicating the validity of further research in this regard, due to the existence of significant differences in the diagnosis and description of ASD.

Social changes, which allow for a faster flow of messages, better contacts between distant places become allies of the unification of societies, but can also improve the research for isolated social

niches. At present, the creation of environments of people with ASD not alienated by society, but now alienating themselves, is observed. It is an expression of obtaining their own identity, the search for support groups and finding their own place in society. It is through adjusting to the changes aimed to respect diversity that ASD is moving away from discrimination and alienation into understanding and social inclusion. It can even be said that openness to learn what has not been considered so far, marginalized, is an opportunity for further development of societies.

Autism, autism spectrum disorders are important terms that should make the public aware of diversity, but also the importance and importance for its overall development. Just as in the knowledge of the other person, one can find oneself; so in the search for understanding what autism is, one can get to know the society better - its structures, functions - and above all, real and not declarative reality. Listening to people recognized as others by the society is therefore a very important task, which should be continued.

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