



Do We Need Autistic Autism Researchers to Understand Autism?



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Abstract: The assumption that autistic individuals do not have the theory of mind – the social-cognitive ability to understand other people by attributing mental states to them – has been widespread in the psychological literature. However, the empirical evidence from the original research and its replications failed to prove and support autistic mind-blindness. Yet, it is still present in literature on autism spectrum. Meanwhile, convincing research, that has been conducted among autistic researchers and their allies, is often overlooked by non-autistic specialists. This paper focuses on how autistic autism researchers have been influencing their field of study and how academy can benefit from their work.

Keywords: Autism; autistic researchers; autism research; theory of mind; neurodiversity; double empathy.

I. What Is Autism and Is It Only a Medical Term?

According to ICD-11 autism spectrum disorder is neurodevelopmental condition characterized by “persistent deficits in the ability to initiate and to sustain reciprocal social interaction and social communication, and by a range of restricted, repetitive, and inflexible patterns of behaviour, interests or activities that are clearly atypical or excessive for the individual’s age and sociocultural context” (World Health Organisation 2019).

However, even though it is mainly perceived as a developmental condition and as such – medical condition¹ – there are also non-medical aspects of this phenomenon. Autism is also a social and cultural construction. Researcher Nick Walker notices that medical approach defines autism through its deficits, calling it the pathology paradigm – its opposite would be neurodiversity paradigm, originating from neurodiversity

¹ What is worth noticing, in previous versions of ICD and DSM classifications autism was called the disorder, not condition. The change has been the result of increasing scientific knowledge and pressure from neurodivergence movement.

movement, based on the assumption that humanity is diverse in the terms of neurotypes (Walker 2021).

Developmental psychologist Steven K. Kapp, basing on social model of disability, argues that more “holistic and social embedded classification” is needed to show not only deficits, but also strength of autism and as a result include autistic people in society (Kapp 2019). Moreover, autism can be also treated as a cultural category (Grinker 2010) – firstly because stereotypical depiction of autistic person influences the way autistic people are treated in society; secondly: autistic community itself creates its own culture (Sinclair 2010; Walker 2021).

Getting out of medical paradigm not only changes the way of understanding and thinking of autism, but also makes way for new study approaches in field of autism research. As an autistic historian of political thought and literature scholar, in this essay I focus on relation between academic narration and autistic community’s perception of autism phenomenon since the arise of neurodiversity movement in late 1990s.

II. Neurodivergence Movement *Versus* Pathology Paradigm

What do autism researchers like Nick Walker, Damian Milton, M. Remi Yergeau, Monique Botha, TC Waisman or Patrick Dwyer have in common? Beside the academic interest, they all also share the neurotype – none of them belongs to the typical developing majority. Does it suggest that there is a connection between studying the autism phenomenon and being on spectrum? As much as such connection between being on spectrum and understanding other people on spectrum may seem explainable, the link between neurotype and research might be far less acceptable. All in all, scientific methodology is considered as objective as possible to be, therefore individual predispositions of researchers should not determine the approach to studied phenomenon. However, even though there are procedures created to prevent the biases in science, they can still occur on every level of the research, and assuming that neurotypical researchers are free from them might be dangerous. One of the main reasons of significant shift in autism studies was the involvement of autistic researchers who proposed new explanations for issues connected to autism spectrum disorder that were already known but remained unexplained.

Before the existence of organized neurodiversity community, discourse around autism spectrum was almost entirely medicalized and based on pathology paradigm (Walker 2021). People on autism spectrum were examined, studied, and analysed mostly by neurotypical experts. Autism itself was presented as a pathology, the impairing disorder that causes the disruption between the autistic individuals and their families and guardians (Waltz 2008). This approach was reflected in the media, that presented autism as an illness and listened only to the stories told by parents and caretakers of autistic people (Hens 2021).

Since the emergence of the neurodiversity movement (Silberman 2015) the question of how autism should be researched arose. Autistic self-advocates disagreed with the medical discourse based on the pathology paradigm (Walker 2021), that dominated in the field of autism research, and argued for changes both in researchers' approach and in interpretation of autism itself. The term neurodiversity assumes that person's neurotype is just one of variables that one characterises an individual, just like gender, class, or nationality (Singer 1999). Neurodiversity movement does not argue against the discourse of difference between people of various neurotypes, but it treats all neurotypes as equal and do not compare them to neurotypicality as a default and desirable one (Fung 2021). According to those premises, autism itself is no longer an impairment.

III. Do Autistic People Lack Theory of Mind?

One of the scientists that based their rhetoric on the difference understood as a deficit was Simon Baron-Cohen, considered an expert in autism spectrum disorder. His research oscillated around the issues connected to his understanding of autism: theory of mind (Baron-Cohen et al. 1985) and mind-blindness (Baron-Cohen 1990) attributed to autistic people. His view² influenced psychology textbooks³ for years, even though there were inconsistencies within his studies (Gernsbacher & Yergeau 2019).

Hypothesis that autism is based on lack of theory of mind was wildly popular among specialists and could be found in psychology textbooks, but during last 20 years researchers provided empirical evidence against it. As Morton Ann Gernsbacher and M. Remy Yergeau showed in their meta-analysis (Gernsbacher & Yergeau 2019) of various research data, not only evidence do not support the idea that autistic people are equally impaired in theory of mind and that theory of mind impairment was unique for autism, but also original findings that led to the lack of theory of mind hypothesis have not been replicated. Moreover, researchers argue that perceiving autism through impairment of theory of mind can be socially harmful. They provided readers with examples of statements that can be interpreted as harmful ones, like words of Baron-Cohen himself, that autistic people "biologically set apart from the rest of humanity in lacking the basic

² Baron-Cohen is also an author of the claim that autism is "a manifestation of the 'extreme male brain', which explains why the condition affects four times as many boys as girls" (Baron-Cohen 2002). He claimed that there were "two neglected dimensions for understanding human sex differences are 'empathising' and 'systemising'" (Baron-Cohen 2021), where empathising was attributed to female brain and systemising to male one. More recent studies (van Eick & Zietsch 2021) undermined this hypothesis. Moreover, the issue of underdiagnosing autism in girls and women because of false stereotypes and associating autism with boys and men (Arky 2023) is still one of the main topics within both the academic and autistic community (Schaeffer 2023; Saporito 2022).

³ It is still great problem in Poland – one of the examples from the Polish literature, depicting how of trusting non-replicable studies can harm autistic individuals, may be notices in an article on preventing bullying of the autistic children (Sekułowicz 2015). Author of the paper keeps using ableist language and includes lack of theory of mind (what is worth noticing, author does not refer to any original source of information, only materials translated to Polish) as one of the reasons that autistic children are bullied.

machinery” (Baron-Cohen 2009).

Authors of meta-analysis noticed that even though autism spectrum includes communication impairment, all theory of mind tasks, that were used in experiments studying theory of mind (including the one used by Baron-Cohen’s team), heavily relied on spoken language and sophisticated vocabulary. Therefore, it cannot be surprising that autistic people, who by definition have some communication problems, were worse in theory of mind tasks than typical developing (Gernsbacher & Yergeau 2019)⁴.

If non-autistic researchers turned out to be susceptible to biases and misinterpretation of data on autistic people, does it mean that academia needs autistic researchers? As much as it is impossible to estimate how important one’s neurotype might be when studying phenomenon based on the neurological differences, one of the methods to find the answer for this question is overviewing the recent autism studies with researcher’s neurotype in mind.

Since neurodiversity movement emerged in the mid 90ties the visibility of neuroatypical researchers grew up. Even if the discourse around autism had not drastically changed, more people started to be interested in conducting studies not focusing on the pathology and impairment aspects of neuroatypical people. As much as academic world is still considered not to be especially autistic-friendly, there are more and more openly autistic researchers in the field of autism research.

IV. Monotropism

One of the concepts embraced by autistic community is the theory developed by Dinah Murray and Wenn Lawson – monotropism. It focuses on the one of the diagnostic criteria – ‘restricted areas of interest’ – as a core of autism spectrum (Murray et al. 2005). Although this concept has been present in academic literature since 1992, it had not drawn much attention of mainstream autism researchers before neurodiversity movement influenced academic world. Therefore, as much as representants of autistic community find it more convincing than many other theories on autism (Dwyer 2021), it still needs to be better researched.

Important factor for this article’s argumentation is the neurotype of researchers working on monotropism – while Lawson has been diagnosed with autism, Murray was not, but many of her autistic friends and coworkers believed she was also autistic (Murray & Lawson 2020). Their work has inspired other autism researchers who consider monotropism to be a crucial component explaining autism phenomenon. One of those scholars is sociologist Damian Milton, creator of double empathy theory.

⁴ All data and research included in meta-analysis has been collected by Gernsbacher in the technical report (Gernsbacher 2018).

V. Double Empathy Theory

The term ‘double empathy’ has been coined by sociologist Damian Milton; in a paper published in 2012 (Milton 2012). Milton reflected on the ontological status of “autism and other neurological disorders, diagnosed by behavioural indicators, and theorised primarily within the field of cognitive neuroscience and psychological paradigms.” Researcher noticed that the existing medical approach was based on the perceived “deviance from the expected functional stages of development” (Milton 2012) and led to treating those on autism spectrum as impaired people who need to be taught how to fit in with the non-autistic majority. Double empathy⁵ theory proposed another interpretation of the difference between majority and autistics, Milton explained that various experiments and research suggest that people on autistic spectrum disorder may not have problems with theory of mind itself, but with understanding neurotypical majority – and *vice versa*, neurotypical majority, including scientists, experimenters, researchers, has difficulties with understanding the autistic minority. Since 2011, when Milton formulated his theory for the first time, multiple experiments have been conducted that suggest that double empathy theory might be correct (e.g., Edey et al. 2016; Shepperd et al. 2016; Heasman & Gillespie 2019) and can be used to improve autism research (Pellicano et al. 2022).

Are there any other reasons why Milton’s writing has been so important amongst the researchers and community? Yes, besides being a sociologist and academician, he is also a father of a child on spectrum and has been diagnosed as autistic himself.

Double empathy theory has influenced the autistic community, it helped strengthening the autistic identity and was used as an argument against impairment of theory of mind amongst people on spectrum. Some autistic self-advocates argued that further change of the language and the discourse around autism is needed (Botha & Cage 2022). The subject keeps being discussed both amongst the self-advocates community and academics. Kourti argues that from Critical Realist standpoint double empathy and monotropism can be treated as examples of transcendental arguments that may constitute a wider autism theory – deeper than those proposed by neurotypical researchers (Kourti 2021).

VI. The Myth of Objectivity

The issue of objectivity is crucial to understand both scientific approach itself, and its failures – some researchers believe that objectivity can be functionally achieved and tend to overlook individual circumstances influencing every research result. However, the history of scientific method teaches that there are no such things as a certainty and

⁵ In further discussions around double empathy, the subject of social and cultural aspects of the empathy occurred – Milton noticed that even the understanding of the term itself may not be the same to everyone because it depends on the definition one uses (Nicolaidis et al. 2019).

full objectivity (Hacking 2015), we find out more and more factors influencing research procedures, its results and interpretation. In the case of autism research, scientist used to believe that being non-autistic guaranteed the objectivity of their work, while autistic person could not be objective in studying their own condition. Meanwhile, as it was mentioned in previous parts of this article, autistic and typical-developing people do differ in their ways of thinking and have problems with understanding each other. It turned out that, contrary to common beliefs, being non-autistic could greatly influence studies, and it was not without the consequence for autistic people.

If subjectivity and susceptibility to bias are impossible to avoid in scientific world, what kind of results do they bring? Monique Botha, autistic autism researcher, describes most common problems stemming from the lack of representation of autistic researchers in the academia and avoidance of non-typical developing perspective (Botha 2021). She explains how the belief in scientific objectivity led to dehumanisation of autistic people, ableism in academy and side-lining autistic expertise. Botha writes in the spirit of standpoint theory⁶, she refers to her own experience during psychology studies in 2010s. As an autistic person she was taught about her “deficiencies” by non-autistic people – she perceived the academical knowledge as “two-dimensional”, while thinking about herself and other autistic people as much “more complicated”, not just lacking theory of mind and needing to be forced to communicate in neurotypical way (Botha 2021). Yet she was not allowed to share her opinion during lectures, because of assumption that as an autistic person she is unable to be objective.

Meanwhile, as I wrote in previous parts of this article, there was no reason to undermine autistic’s experience and assume that being typical-developed person guaranteed any objectivity – all in all, Botha’s lecturers cited mind-blindness theory, theory that was unscientific and incorrect from the beginning. Botha is not the only autistic person in the academy that struggled to have her voice heard (Bertilsdotter Rosqvist 2019). Moreover, besides aforementioned problems TC Waisman talks about cultural barriers resulting in mainstream research omitting non-white communities (Khamsi 2022). When it comes to assumed objectivity of non-autistic people’s research, Kourti (2021) formulates the counterargument: such research, without the insight of autistic individual, is surface-level and can only describe “what autism looks like, not what autism is”.

What were the consequences for autistic community that autistic researchers refer to? Steven K. Kapp argues that: “harms of the medical model heightened by these [social deficit] theories include dehumanisation that denies basic respect and dignity, pathologisation of neutral and positive differences, reductionism to a social disorder despite complex traits and sensorimotor underpinnings, and essentialism despite autism’s fluid boundaries” (Kapp 2019). Various studies on autistic people provide data about higher rate of suicides (Hirvikoski et al. 2016), minority stress (Botha & Frost

⁶ Standpoint theory, originating from feminism theoretical position, argues that knowledge stems from social position (Borland 2020).

2020), discrimination by state forces (Home Office 2018; Ball, Jeffrey-Wilensky 2020), school problems (Timpson 2019), high unemployment and bullying (Shattuck et al. 2012). Common methods of therapy like Applied Behavioral Analysis is ethically controversial (Shkedy et al. 2021), and may result in trauma in autistic children⁷.

VII. What Should Be the Goal of Autism Research

Before double empathy theory and discrediting of mind-blindness theory, when neurodivergent people had very small or none influence on the academic world, autism research focused on seeking the causes of autism, its etiology or counting the percentage of autistic people (Khamisi 2022), and even the treatment for this condition (Autism Research Institute). But it is not the knowledge that autistic community prioritizes. They wish to focus on systemic discrimination, barriers in everyday life and (positive) exploration of atypical identity (Autistic Self-Advocacy Network 2022). Not without significance is also the impression that autistic narration and autistic stories still mostly do not belong to autistic community (Yergeau 2018).

In order to gain influence over autism research, autistic community networks engaged in supporting autism research and even created their own research institutions and organizations gathering neurodivergent academics and their allies. For example: in 2006 Academic Autism Spectrum Partnership in Research and Education (AASPIRE 2020) was founded; Autistic Self Advocacy Network offer their help in Community Based Participatory Research; Sandra Thom-Jones' website Autistic Professor lists academics openly diagnosed with autism and their research (Thom-Jones 2021). Aforementioned Damien Milton is part of the Participatory Autism Research Collective⁸. Autistic researchers became more visible in already existing institutes, like Autistic Research Committee in International Society for Autism Research, and media (Nuwer 2020) connected to autism research.

How should autism research, as a discipline, evolve? As director of Centre for Autism Research in Africa Petrus de Vries (de Vries 2023) noted, this question does not belong to medicine and science alone, it is also a philosophical issue that firstly demands an answer to the other question: how autism itself should be treated. He notices that different communities need different studies and researchers should take into the account the "social responsiveness", meaning that their starting point needs to be to seek a true understanding of the "social and societal" needs and priorities of autism stakeholders at all levels of society in each of our own communities.

Sandra C. Jones notices that many researchers grew up in the world, where autism

⁷ ABA (in Polish: Stosowana Analiza Zachowania – SAZ) is still common therapy for autistic children in Poland, its harmful results describes Joanna Ławicka in her book *Jarzmo* (Ławicka 2022).

⁸ See: <https://participatoryautismresearch.wordpress.com/about/>

research was “conducted on autistic people” but over the time it evolved to “include research conducted with autistic people (...) and now to include research conducted by autistic people” (Jones 2021). What is important for autistic community, including autistic researchers in autism research results in improving the quality of lives of autistic people, because they are familiar with issues that are actually influencing the functioning of autistic person while neurotypical researchers are only able to try to understand them – what in the past resulted in ascribing neurotypical ideas to autistic persons (Jones 2021).

Autistic autism researchers agree with each other that the participation of autistic community (Fletcher-Watson et al. 2019), taking into the account their opinions, and overcoming discrimination is essential to conducting successful and meaningful research. One of forms of such inclusion of autistic individuals is Participatory Autism Research – research conducted by academician in partnership with autistic person (or researcher) in the spirit of “nothing about us without us” idea (Chown et al. 2017).

Conclusion

Autistic researchers and their allies claim, that narration based on pathology and deficit paradigm caused by ableism of academical community (Nuwer 2020) was one of main factors facilitating systemic discrimination of autistic people. The solution of this problem may be the increasement of autistic community participation in autism research and cooperation of the people of various neurotypes while studying autism phenomenon. As much as it is impossible to claim with full certainty whether autistic researchers were needed to better understand autism, so far it was their contribution that pushes the studies in the new direction.

There are much more issues to explore within autism studies. Autistic researchers I referred to in this article represent different fields of studies, including sociology, cultural and literature studies. The response to traditional autism research are (renewed) critical autism studies (Woods et al. 2018), that try to include autistic voice into research conducted by academicians and validate the work done by autistic researchers. This form of critical autism studies, along with neurodiversity studies (Rosqvist et al. 2020), follow the neurodiversity paradigm, does not treat neuroatypical individuals as automatically impaired ones and tries to reflect the needs of researched community.

Similar to critical disability studies, critical autism research is not limited to medical aspects of autism. For example, Kourti (2021) notices the need for some form of philosophy of autism that could counter the traditional narrative, Yergeau (2018) explore the rhetoric around autism, TC Waisman (Khamisi 2022) and Melissa Simmonds (Milton & Ryan 2022) study how ethnicity influences the chance of receiving diagnosis and treatment of Black Autistics. Both critical autism studies and neurodiversity studies are relatively young and interdisciplinary fields of research and there are many unexplored aspects connected to autism that are waiting to be studied.

From my observation as a Polish scholar, the subject of autistic autism research is still unexplored in Poland and Polish academic world. Most of the research and support is still directed towards parents, guardians of autistic people and autistic children. As much as idea of neurodiversity is already present in autistic community, there are few academic psychological publications that explore this idea. Polish (adult) autistic community keeps developing mostly in social media (mostly in the form of Facebook groups) or around communities and institutes led by autistic self-advocates (like *Dziewczyny w Spektrum Foundation*). The mind-blindness theory is still popular in Poland and the knowledge of updated academic research and concepts like monotropism and double empathy is not widespread. As much of Polish research has been focused on children and functioning of families with autistic individuals, there are not many studies conducted on (not to mention with partnership with) autistic adults that are not institutionalized or living with parents (Prokopiak 2020). Perhaps introducing Participatory Autism Research⁹ would provide research more valuable for Polish autistic community.

Analysis of the state of knowledge on autism presented in Polish books and publication may a prospective issue to research. There is lack of analysis of the rhetoric and narration around autism in media and popular literature in countries like Poland, where the ideas of neurodiversity studies and critical autism studies are not well known. Finally, the works of autistic artists and writers may be a source of valuable information on autism and autistic identity that researchers may explore.

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⁹ The academical initiative that follows neurodiversity paradigm is Stigiversity Lab associated with Psychology Institute of University of Silesia.

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