

AUTISM AND PARTICIPATION IN CULTURE

Marta Wiszniowska-Majchrzyk¹, Zdzisław Majchrzyk²

¹*Philosophy of Culture Dept., Cardinal Stefan Wyszyński University, Warsaw, Poland,* ²*Forensic and Penitentiary Psychology Dept., Cardinal Stefan Wyszyński University, Warsaw, Poland*

Key words: autism, Asperger's syndrome, splinter skills, talents, retrospective diagnoses of autism, cultural definitions of autism, computer culture, cultural component in diagnosing autism.

Summary

Autism and autism related disorders were diagnosed at the beginning of the 20th century, yet the symptoms seem to have been with humanity from time immemorial. Recent studies in autism and Asperger's syndrome go in two directions; retrospective that is diagnosing famous figures from the past, and researching present day epidemic spread. In spite of new diagnostic methods, the disorder still remains difficult to define, assess and treat.

Basing on the already diagnosed cases, the authors put point to another dimension, so far neglected, namely the role of culture, cultural background, and cognitive-informative message to help understand and diagnose the impairment. Several reported cases reveal either splinter skills or exceptional talents, both in traditional and new computer culture. In our age of virtual and real realities intermingling, possibly autistic and exceptionally talented individuals have the answer to the question: how one can perceive and reflect upon the world around us.

Finally, our set views on what norm and pathology are have to be constantly revised.

Introduction- sketching study areas

Why autism? When regarded from the present day perspective, autism and autism related disorders seem to have been with humanity from time immemorial but in a strangely hidden form, best described with the term hardly ever used in medical and psychological studies – *avant la lettre*, denoting that some phenomena had been known before labelled, described or named. When in 1912 Eugen Bleuer identified the symptom of autism manifesting itself by the absence of real disposition toward life necessities

and an inclination to replace reality with dreams and delusions, the term he used came from the Greek word *autos* (meaning self). Hans Asperger, whose findings have been closely linked with Bleuer's defined the symptom of his name in 1944 [13].

Since then autism appears one of the phenomena, which is on the rise. Thus a brief survey of definitions and developments seems advisable:

- Autism is one of a group of serious developmental problems called autism spectrum disorders that appear in early childhood, usually before the age of 3. Though symptoms and severity vary, all autism spectrum disorders affect a child's ability to communicate and interact with others.

- The number of children diagnosed with autism appears to be rising. It is not clear whether this is due to better diagnosing and reporting autism or a real increase in the number of cases or both.

- While there is no cure for autism, intensive, early treatment can make a big difference in the lives of many children with the disorder.

- Symptoms can be divided into three main groups of impairments in social skills, language, and behaviour [2].

A sustained interest with autism suggests new guidelines as recent findings in diagnosing autism opt for bio-medically based treatment introducing complex and advanced testing [19,22].

Plenty of studies available discuss several aspects of the condition, stressing that each patient is different, and symptoms can be misleading, the term itself stretchable, including other conditions such as Asperger's syndrome [15].

Why culture? What is culture? Culture is considered one of the most difficult terms to define [7]. In short means a general process of intellectual, spiritual and aesthetic development, a particular way of life, whether of a people, period or a group; the works and practices of intellectual and especially artistic activity [6]. But culture can hardly be contained in these three items. It is better defined as:

‘A culture, while it is being lived, is always in part unknown, in part unrealized. The making of a community is

always an exploration, for consciousness cannot precede creation, and there is no formula for unknown experience. A good community, a living culture, will, because of this, not only make room but actively encourage all and any who can contribute to the advance in consciousness which is the common need. Wherever we have started from, we need to listen to others who started from a different position. We need to consider every attachment, every value, with our whole attention; for we do not know the future, we can never be certain of what enriches it; we can only, now, listen to and consider whatever may be offered and take up what we can.' [24:320].

The above descriptive definition, by one of the most prominent British cultural theorists of the 20th century, takes up new ideas, such as the need to encourage contribution toward creating culture, an obligation to pay attention to the opinions different from ours, and above all the need to cherish such contributions for they may become crucial for future culture and society. Clearly then, as Williams opts for participation, we may as well try to define it. According to OED participation is the fact or condition of sharing in common (with others or with each other); also association with partners, partnership, fellowship, profit sharing. It seems proper to add another culturally specific term that of *participation mystique* - imaginative identification with people and objects outside oneself, regarded as an attribute of primitive peoples by the French anthropologist Lucien Lévy -Bruhl (1857-1939); merging of individual consciousness with that of a group or with the external world [16].

Why concentrate on autism? The reason seems simple, because of the data available, which might be defined in terms of pandemic or epidemic spread. According to American sources diagnoses of autism doubled nationwide. The study released in April 2012 by the California Department of Developmental Services reports a dramatic and unexplained increase of autism in children throughout the state. According to the study, the number of autistic children in California increased from 10,360 in 1998 to 20,377 in 2002, confirming a trend first reported in a similar study published by the state in 1999. That one showed a 237 percent increase in autism diagnoses over the previous 12 years [4].

Since 1987, the total population of California children diagnosed with autism has increased by 634 percent with no sign of lessening. Between January and April of 2012, 832 cases have been reported, setting the rate of almost 10 new cases a day. Because the term autism encompasses such a wide spectrum, the study quoted excludes Asperger's syndrome and pervasive developmental disorder, overlooking the conditions that exist on the ends of the spectrum.

The final comment of the report catches one's eye: 'The number of children with autism has increased significantly in Canada and the United States, but the cause - whether it's environmental, genetic, or a result of better diagnostic tests - remains an elusive mystery' [5].

It is in the nature of medicine and psychology to focus on negative aspects called symptoms. Perhaps it is positive psychology that remains an exception that proves the rule. It is also true that diagnosing autism and related impairments has medical and psychological consequences.

This paper aims at showing that in medical and psychological diagnoses something else escapes specialists' attention. With the attention turned to the so called quality of life, one must realize how stigmatizing such psychiatric and psychological diagnosis used to be and still to a degree is, how devastating for the individuals and their families, and the individual's inalienable rights in democratic societies (the right to get education, to contract a marriage, to enjoy civil rights, etc.). So the question may be asked whether autism and quality of life are mutually exclusive or not.

The evidence that it may not be the case comes from various quarters. More and more individuals come up with their stories of autism or Asperger's syndrome. When diagnosed explained and accepted, it may lead to bettering one's existence, until then rather miserable. The case in point is a recent book by Marc William Pulver [18]. More evidence comes when the parents of autistic children share experiences. Books by parents and researchers of autistic children compellingly show exceptional skills of those children, and opportunities for leading rewarding lives, professional - the case of Temple Grandin or Gregory Blackstock, Jessica Park and Ping Lian Yeak, and several young artists, whose talent shows already in early teens [14].

There seems to be yet another connection between autism and culture. It is either a trend or fashion to look for the cases of retrospective autism that is examining the evidence that comes down to us concerning the lives, activities and achievements of various well-known figures. Several researches have been conducted to examine *ex post* the condition of such historical figures as Michelangelo, J. Joyce, W. B. Yeats, W.A. Mozart, B. Bartok also presidents and kings, poets and great scientists and philosophers (I. Newton, A. Einstein, A. Turing and N. Tesla), also Hitler and a series killer Jeffrey Dahmer [19].

Michelangelo - retrospectively diagnosed autistic? Scepticism concerning the method and interpretation of such evidence was only to be expected. In 2004 the Journal of Medical Bibliography, published by the Royal Society of Medicine Press, came up with a significant paper rekindling the discussion on retrospective autism. Dr.

Muhammad Arshad presented new evidence suggesting that Michelangelo suffered from Asperger's disorder, or high-functioning autism. His diagnosis was based on the following symptoms recovered: communication problems, difficulties with social skills, lack of security and ambition, repetitive behaviour, a limited range of interests and co-ordination problems. Michelangelo was a loner, self-absorbed, concentrated on his masterpieces. Although the author claimed that Michelangelo was 'impotent, a paedophile, or a homosexual and had contracted syphilis and experiencing anxieties about sex', it was his anxieties about sex that led to such conclusions [1].

The article met with huge response, highly critical and accusing the author of using medical jargon and showing lack of understanding. One opponent wrote 'This article is yet another work infested with psychiatric jargon and nonsense as well as psychiatric biases' [11].

Dr. Ashard's discussion seems well documented and perhaps professionally convincing. Yet examining just a fraction of Michelangelo achievements, one cannot help but wonder which is more important – the medical diagnosis or artistic achievement. The fragment from the Sistine Chapel, perhaps the best known central scene of the creation of Adam is freely available on the Internet, in illustrated guides to Rome, and other endless sources, and remains a pillar of Western culture (Fig 1). And it is not only for believers, for the creation of Adam carries a brilliant symbolic picture of the most mysterious moment that concerns the beginning of human race. Putting aside its religious content, the scene also conveys a powerful symbolic and a philosophical reflection. One has to decide which comes in first – Michelangelo as an individual, obviously far from perfect, perhaps suffering from several impairments, or Michelangelo the artist. The answer seems obvious.

In view of such conflicting evidence and opinions, the question Francesca Happé asked is fundamental to explo-



Fig. 1. Michelangelo (1475-1564) Creation of Adam

re the link between culture and autism. The question was: 'Autism: cognitive deficit or cognitive style?' [9]. To examine the problem, more studies on exceptional artistic competences appeared, and such terms as splinter skills [10] and exceptional talents [21] were singled out.

The case of Michelangelo may be too shaky and of mere specialists' interest. But the case of Stephen Wiltshire is a success story of a 39 year (born 1974) old Briton of West Indian origin, now a famous artist who creates huge drawing and paintings from memory. In 2006 he was awarded an MBE for outstanding achievements. He needs a 20 minute helicopter ride over New York to draw it completely from memory in a week long session. Wiltshire is autistic and not aware of it (according to his family). He did not speak until he was 5 and his first words were to ask for some paper and a pen to draw. He developed as an artist due to (as it appears) his supportive family and teachers. His video interviews show him a man of halting speech and childish naivety. He communicates in short sentences, for instance saying that drawing from memory is easy. He says some people say to me your work is brilliant, and the interviewer says: And you like it? Yes. – is the answer and a smile [25].

Both retrospective diagnoses and current instances validate the existence of splinter skills and exceptional talents. They also confirm what was said at the very beginning of the paper that autism must have been an impairment well known but not singled out or properly diagnosed. The case of Stephen Wiltshire indicates that talents and skills can be encouraged and developed in the process of intelligent coaching that evades and diminishes negative aspects of autistic behaviour and teaches to reinforce positive ones.

Computer culture – where culture and civilization meet. Establishing a close link between autistic people and their special skills does not exhaust possible correspondences. The second half of the 20th century witnessed the astonishing progress in culture and civilization, computer culture in particular. It also became evident that culture and civilization overlap in the following definition of civilization as a) a relatively high level of cultural and technological development; *specifically*: the stage of cultural development at which writing and the keeping of written records is attained ; b) the culture characteristic of a particular time or place. [3].

We have also come to appreciate a variety of artefacts, including cultural ones that are computer- created. But thriving face books and twitters, computer games, memes and other new forms of entertainment belong to international business, along side with banking, computer programming, computer sciences, but also hacking. These new cultural

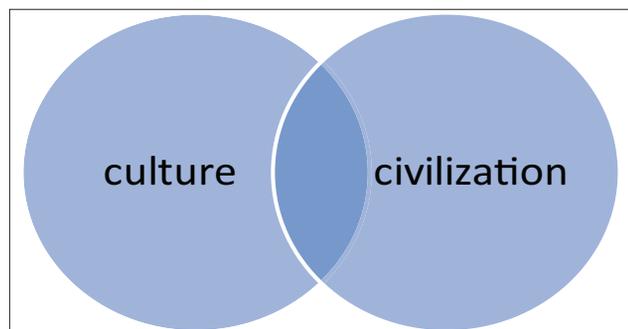


Fig. 2. Culture and civilization overlapping

activities seem to induce such behaviours that come under the category of autism and autism related disorders. As in the previous part of the paper, let us look at the case of retrospective autism.

The case described recently is that of Alan Turing (1912-1954), a mathematician and logician, codebreaker working for the government during World War II, cryptanalyst and computer scientist. He was instrumental in LU decomposition, testing artificial intelligence, and creating computer games [22]. Turing was homosexual convicted for what used to bear the legal label of ‘gross indecency with another male’ in 1952 (in 2012 he was posthumously granted statutory pardon). He was given a choice of serving a prison sentence or undergoing chemical castration. He died suicidal (or accidental) death in 1954 of cyanide poisoning. The scene of death was carefully (?) and strangely (?) arranged. A half eaten apple found by the body had no traces of poison. But the scene was symbolic for it referred to Turing’s favourite Disney film *Snow White and the Seven Dwarfs*, especially the scene of the Wicked Queen poisoning the apple [8].

There seems to be an appalling discrepancy between Turing’s intellectual abilities and his fascination with a film for very young children. It was James [12] who retrospectively diagnosed Turing in 2005 along with twenty other artists and scientists of the past.

Again, if retrospectively diagnosed disorders leave room for doubt, some present-day cases signalize a link between computer culture, in its highly creative and advanced version, and autism and autism related disorders. Adrian Lamo is a young, clever and for a long time undetectable computer hacker, who was hospitalized in 2010, having been on antidepressants since 2006. It was during his hospital stay that he was diagnosed with Asperger’s syndrome, which he believes, explains both his successful

hacking and communication difficulties. Lamo maintains that his hacking (never to steal anything but for the sheer fun of it) required no particular technical skills, but just ‘a lot of hunch work’. He says: ‘I have always maintained that what I did isn’t necessarily technical, it’s about seeing things differently /.../ so if my brain is wired differently, that makes sense.’ Here Lamo speaks the way; artists usually speak, unable to explain how their minds work. Such special ability has another dimension when Lamo describes his communication difficulties. He says: ‘Talking to strangers was really hard for me /.../ I had to script it all in my head and act out normal behaviours in a very conscious way. Essentially, I had to learn how human beings act’ [17].

Conclusion

Helene Ouellette-Kuntz, a Queen’s University professor, said she suspects ‘up to 2/3 of the increase in autism may be due to growing awareness and changes in diagnostic practices.’ But additional research suggests that even after accounting for these factors, ‘a third of the observed increase in the prevalence of autistic disorder between 1996 and 2004 could not be explained by increased diagnosis alone.’ The number of children identified with the disorders ranged from one in 210 in Alabama to one in 47 in Utah. The largest increases were among Hispanic and black children [5].

High incidence of autism and autism-related conditions among computer hackers and successful computer inventors (Bill Gates – autism suspected, Adrian Lamo and Gary McKinnon – autism diagnosed, Alan Turing- retrospectively diagnosed). There is no research on that but anecdotally a lot of them are drawn from the computer field, particularly the logic – heavy world of coding.

Considerable difficulties in medical diagnosis of autism and Asperger’s syndrome, the growing number of ‘borderline’ cases, a mention that Hispanic and black children makes in indispensable to openly accept that at the moment there are no fully reliable medical tests to solve the problem.

However, there is a lot of evidence, accumulating all the time, that autism and Asperger’s syndrome have a different dimension. Perhaps cultural milieu should be included in the process of diagnosing. Perhaps it might be for the benefit of those under surveillance that their special skills are tested, and their cultural background reviewed.

Computer related cases of diagnosed disorders may indicate yet another procedure. The life style of those diagnosed or perceived as autistic should be carefully reviewed. In our age of virtual and real realities intermingling, possibly autistic and exceptionally talented individuals have the answer to the question: how one can perceive and reflect the world around us.

Finally, our set views on what norm and pathology are have to be constantly revised.

Literature

1. Arshad M. Was Michelangelo autistic? <http://www.medicalnewstoday.com/releases/8702.php> (acc. 10.08.2013).
2. Autism <http://www.mayoclinic.com/health/autism/DS00348> (acc. 10.08.2013).
3. Civilization (definition). <http://www.merriam-webster.com/dictionary/civilization> (acc.10.08.2013).
4. Clinical Specialities Services <http://www.lpch.org/clinicalSpecialitiesServices/ClinicalSpecialities/Psychiatry/autismQA.html> (acc. 8.08.2013).
5. Ctv.news.ca <http://www.ctvnews.ca/health/as-autism-rates-rise-in-canada-doctors-search-for-answers-1.1264677#ixzz2brblutaN> (acc. 8.08.2013).
6. Culture (definition). Oxford English Dictionary. Second Edition on CD Rome.
7. Eagleton T. The idea of culture. Oxford, 2000.
8. Garner A. My hero: Alan Turing. <http://www.guardian.co.uk/books/2011/nov/11> (acc. 20.08.2013).
9. Happé F. Autism: cognitive deficit or cognitive style? Trends in Cognitive Sciences 1999; 3(6.): 216-222.
10. Hermelin B. Bright splinters of the mind. London, 2001.
11. Jalowski C. The Divine Michelangelo Buonarroti. <http://www.medicalnewstoday.com/releases/8702.php> (acc. 20.08.2013)
12. James I. Asperger's Syndrome and high achievement: some very remarkable people. London, 2005.
13. Korzeniowski L, Płużyński S. Encyklopedyczny słownik psychiatrii polskiej. Warszawa, 1986.
14. Mullin J. Drawing autism. Brooklyn. N.Y. 2009.
15. National Institute for Health and Care Excellence. Autism +diagnosis+in +children+ and +young +people+ Evidence+ Update +April+ 2013.pdf- Adobe Reader (acc. 30.05.2013)
16. Participation (definition) Oxford English Dictionary. Second Edition on CD Rome.
17. Poulser K. Kevin Poulsen, Ex-hacker Adrian Lamo institutionalized, diagnosed with Asperger's <http://www.wired.com/threatlevel/2010/05/lamo/> (acc. 12.08.2013)
18. Pulver M.W. Living life with autism: the world through my eyes. Indianapolis, 2012.
19. Retrospective diagnosis of autism. http://www.Wikipedia.org/wiki/Retrospective_diagnosis_of_autism (12.08.2013)
20. Shaw, W. Dr William Shaw, Nowe testy w autyzmie/PDD (acc. 30.05.2013).
21. Treffert DA. Extraordinary people: understanding the savant syndrome. N.Y. 2000.
22. Turing A. http://en.wikipedia.org/wiki/Alan_Turing (acc. 20.08.2013).
23. Vegamedica <http://www.vegamedica.pl/polecamy/autyzm-leczenie-biomedyczne/materialy-z-ii-miedzynarodowej-konferencji-na-temat-zaburzen-spektrum-autyzmu/> (acc. 21.09.2013)
24. Williams R. Culture and society 1870-1950. Harmondsworth, 1971.
25. Wiltshire S. http://www.stephenwiltshire.co.uk/download_video.aspx?Id=1507 (20.08.2013)

AUTIZMAS IR DALYVAVIMAS KULTŪRINIAME GYVENIME

M. Wiszniowska-Majchrzyk¹, Z. Majchrzyk²

Raktažodžiai: autizmas, Aspergerio sindromas, fragmentiniai sugebėjimai, talentai, retrospektinė diagnozė, kultūrinė autizmo dimensija, kompiuterinė kultūra, kultūrinis komponentas diagnozuojant autizmą

Santrauka

Autizmas ir autistiniai sutrikimai buvo diagnozuoti XX a. pradžioje, bet šie simptomai lydi žmoniją nuo neatmenamų laikų. Naujausi autizmo ir Aspergerio sindromo tyrimai vyksta dviem kryptimis – retrospektiškai, t.y. diagnozuojant įžymius praeities žmones ir siekiant išaiškinti paplitimą šiais laikais. Naujausi diagnostikos metodai dar nepalengvina išaiškinimo, matavimo ir gydymo. Pagal jau turimus atvejus autoriai siūlo kitas dimensijas, būtent kultūros vaidmenį, kultūrinį foną ir kognityvinį-informacinį signalą, kas padėtų suprasti ir diagnozuoti šį defektą. Keli pateikiami atvejai parodė arba fragmentinius sugebėjimus, arba išimtinis talentus, tiek tradicinėje, tiek ir naujoje kompiuterinėje kultūroje. Šiandienos virtualios ir realios tikrovės samplaikoje galbūt tik autistai ir išimtiniai talentai gali suvokti ir apmąstyti mus supantį pasaulį. Pabaigai: mūsų samprata, kas yra norma ir kas patologija, turi būti nuolatos revizuojama.

Correspondence to: z.majchrzyk@neostrada.pl

Gauta 2012-02-05