

THE ADULT WITH AUTISM SPECTRUM DISORDER – BETWEEN MYTH AND REALITY

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Abstract: In Romania, until 2013, the person with autism, who had already turned 18 years old, was included under another diagnostic category. It was as if the adult had been cured or as if the disease did no longer exist.

With regard to the field literature, one can notice the lack of books written about this disorder among adults. A mere Internet searching reveals thousands of articles and books dedicated to the children with Autism Spectrum Disorder, but as for the adult who has this condition, except for a few autobiographies and some articles concerning the quality of his life, the experts paid far too little attention to this subject.

As a result, there occurred a lot of myths, stereotypical judgements and preconceptions against the adult with autism, which led to a series of discriminatory behaviour, resulting in a diminished quality of life for people with ASD.

The aim of this paper is to make an analysis of the myths spread among the general mentality. Subsequently, the myths are going to be demolished. Finally, the paper will suggest several alternative ways of thinking, ways meant to improve the life's quality of adults with autism.

Keywords: Autism spectrum disorder, adults, quality of life, myths, misconception.

1. The theoretical framework of the problem addressed

The person diagnosed with autism until 2013, who was over the age of 18, was included in another category of nosography. Ana Dragu, - president of *Autism Europe* -, wrote in autumn 2012 that "Romania is the only state in the world where autism is eradicated at the age of 18. In Romania there are no autistic adults " "(<https://www.totb.ro/ieri-autist-azi-schizofrenic-despre-cum-a-eradicat-statul-roman-autismul-in-randul-adultilor/>). It is as if the adult with TSA has healed or does not exist anymore, knowing the specifics of the condition, this is impossible to accept.

Along with changes in psychiatric nosography through the advent in 2013 of the 5th edition of the Manual of Diagnosis and Statistics of Mental Disorders (DSM V, 2013), but also because of the lobbying made in addition to the various decisional factors in our country by several Associations and Foundations involved in mental health activity, the reality of this adult condition has not been challenged.

Regarding in the speciality literature, we note the lack of works dedicated to this disorder in adults.

A simple internet search reveals hundreds of books and articles devoted to children with autism, but to the adult with this condition, except for a few autobiographical works (eg those of Temple Grandin, translated and published in our country in 2013) , or Donna Williams (translated and published in Romania in 2015) and some articles based on the quality of life for adults with autism, the specialists have focused too little on this subject.

Yet, it is noteworthy in this context the contribution of M.Seltzer and his collaborators, who in 2004 reviewed all the existing studies up to that point on the trajectory of development in adolescents and adults with TSA.

The specialists recognize an essential aspect: in the light of the significant changes that have occurred in the definition and diagnostic criteria of autism, in the last decade the mapping of the TSA from the adult perspective has been complicated and sometimes it has caused some errors. (Seltzer, M. M., 2004, pp. 234).

The authors found 26 types of different studies:

- *longitudinal studies* (based on records and clinical references)
- *retrospective studies* (based on the database of different clinics)
- *transversal studies* (based on clinical references or databases) (reader Seltzer, M.M., 2004)

These studies were conducted between 1985 and 2003, with male and female respondents, adolescents and adults. In general, the procedure used in the studies is the application of - the revised version of autism diagnostic interview - ADI-R (Autism Diagnostic Interview-Revised), considered "the gold standard" in ASD evaluation.

The results of these studies merge in the same direction: "Despite the variability in diagnostic practice and the differences in experimental design, population sample, and measured measurements, the accumulated evidence indicates that the *symptoms of the ASD nucleus improve during adolescence and maturity*. It is important to note that, still, the improvement has not been visible in all individuals, and even in those where improvements have been observed, *changes are not sufficiently substantial to insert the individual into the rate of normal functionality*. " (Seltzer, M.M., 2004, pg. 236).

Beyond the scientific circles, in the ordinary world, where these atypical people have to find their place, there is still a multitude of myths, stereotypical conceptions and prejudices about the adult with autism, which also entails a series of discriminatory behaviors, having result in a decrease in the quality of life for people with Autism Spectrum Disorder (ASD).

On the one hand, this trend is understandable. Every psychiatric diagnosis is a pattern in which we try to press the extraordinary natural variety. It is one of the reasons why we oversimplify and make hasty generalizations. So, a series of *myths* about the different psychiatric conditions are born here. At the same time, they also appear from the perpetuation in the literature and therefore - through the various ways to popularizing science - in the collective mentality, of some theories, assumptions, etc., which seemed valid at some point.

Anyway, our mind is made to work with categories and prototypes, so the tendency for stereotyping is a general human one.

Synthesizing the lack of studies dedicated to the adult with Autistic Spectrum Disorder, the errors in these studies, recognized by the world of specialists, the legislation in the field of mental health (in Romania), together with our need to resort to prototypes, led to the formation and perpetuation of some myths, prejudgments and stereotypical ideas on autism in general and the adult with TSA in particular.

2. Research methodology

Our research took place between February and June 2017 and aimed **objectives** like:

- catch and analyze the myths circulating in the collective mentality;
- suggest alternative ways of thinking to help increase the quality of life to adults with autism.

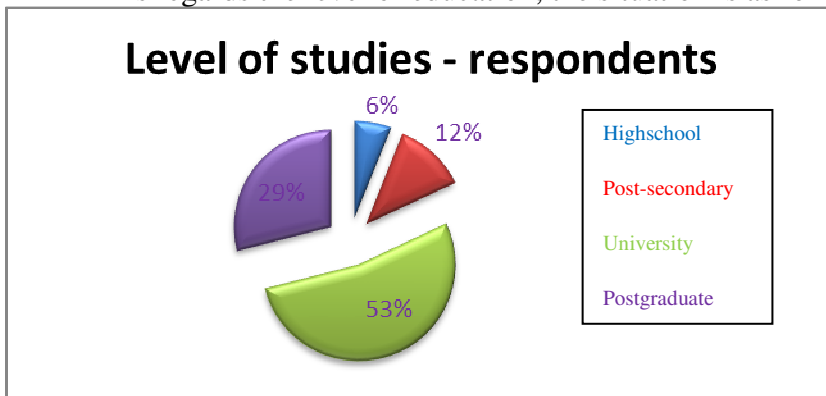
2.1. Tools used

We made a questionnaire, consisting of 12 questions; every question is built around an opinion whose existence in the collective mentality in Romania we wanted to verify. It also contains an introductory part in which the respondents mentioned: gender, age and level of education (the last graduate school).

Its essential characteristics are: *self-administered* (respondents have sent the questionnaire to the administrator with completed answers) *with closed questions* (answers are already stated) *scaled in four different possible answers* (does not contain the neutral response): 1 = total disagreement; 2 = partial disagreement; 3 = partial agreement; 4 = total agreement.

The number of respondents to the questionnaire was 168 people - 76 men and 92 women - aged between 24 and 56 years.

As regards the level of education, the situation is as follows:



of 5 adults with TSA (4 males and a woman) on how to feel the atypical difficulties in relation, the way they perceive of this perception on their lives.

Through the **interview** we have obtained essential data about personal, family and psychiatric history as well as the present state of each participant in the group, their desires and aspirations, frustrations related to their condition.

From the perspective of our work, we were particularly interested in the confrontation between what (after processing data from the questionnaire) emerged as a stereotype about their category and the reality described by those who live it (adults with TSA).

2.2. Processing of the results

2.2.1. Myths and misconceptions identified

The first myth identified was that of the **rarity of the condition**. Our study has shown that most respondents *consider that Autistic Spectrum Disorder is a rare condition*: 43% - partial agreement and 18% - total agreement. There is a possibility that the lack of information through the media or the lack of interest on the part of public authorities that fail to adopt even the methodological norms of an Order (Order No. 968-5194-714-1945-2016, which recognizes the existence of the person adults with TSA and provides its social protection system) has made a major contribution to **the credibility of this myth**.

Although the epidemiological studies on the adult population are lacking, as the incidence of the phenomenon has increased so much in recent years (a study conducted by Prof. Iuliana Dobrescu in 2017 and conducted on the school population in Romania finds a 14% incidence of this condition), we expect that in 10 years from now on, we will have a significant segment of the population of adults with autism.

Another myth circulating (being probably an effect of movies such as Temple Grandin or Rain Man) is that **autism means either extraordinary abilities or serious disability**. As we expected, **the idea of spectrum** with everything it involves (varying degrees of severity and great variability of symptoms) is completely unknown to the general public. It's barely gaining weight in the world of specialists.

In relation to it, there is a strong belief (76% of respondents) in the link between IQ and functionality. In fact, being functional is different from having a high IQ. Being functional means

adapting - or adapting involves a sum of abilities that people with autism do not have as developed as neurotypicals, a certain bundle of these abilities and their structure. People with autism have what they call *splintered skills*.

The third myth is that TSA is a disease. In fact, autism is not a disease, it is a neuro-atypical condition. It is not limited to the medical model of the disease, we can not talk about healing, but only about recovery, within certain limits, because the neuro-atypic will never be a neurotypical. It is not a typical *defect* that needs to be repaired (we found this point of view in the literature, see Silberman, S, 2016).

One of the prejudices acquiesced by most of the subjects - 56% - with serious repercussions on how people with TSA will be treated is that they are not capable of relationship, they do not want friendship, friendship, love.

As can be seen from interview transcripts, the 5 adults with spectrum disorder are capable of affective investment, attachment, looking for meaningful relationships, even if they do not always know how to initiate them or can not understand how we, the typical, react.

Another misconception (related to the previous one) is that people with autism do not want to communicate or do not care about communicating.

It is true that some of them are and remain nonverbal, sometimes despite the therapeutic efforts.

Of those who later became verbal, many say that they wanted to communicate but could not, they did not have the means to do it. This is all the more so as in communication, it happens to take everything literally - or communication is a much subtler matter, not only by the spoken word, but by all that is nonverbal language and paraverbal indices that for people with TSA it is difficult to decrypt them.

There were also opinions in respect of which our prediction was not verified:

Most respondents disagree that *adults* with TSA may not be *useful to society*: 58% - total disagreement and 14% - partial disagreement.

Also, the respondents to our questionnaire considered 46% (total agreement) and 26% (partial agreement) that *adults with TSA can work*. This opinion, closely related to the one previously examined - *adults with TSA can be useful to society* - the results are somehow predictable.

We were pleased to note that, at least at the declarative level, the respondents do not agree with the institutionalization of the persons with TSA, 82% of the respondents expressing this.

2.2.2. Discussion Group

The subjects of the discussion group signed the informed consent and allowed me to use fragments of the discussions during the 5 months in which the group operated. They will appear in this material only with the initials.

M.P. is 42 years old and currently lives from the disability allowance earned.

He attended the *Tudor Vianu* High School, the Faculty of Automatics, and then he was a university assistant for 7 years, a period he described as a nightmare and when he thinks about that period says he's got symptoms of PTSD (posttraumatic stress disorder).

R.S. is 32 years old, followed firstly the Faculty of Philosophy, a master in philosophy, then started a doctorate which he had to abandon for financial reasons. He then graduated the Faculty of Theology. He is currently looking for a job. He has gone through the last year through over 70 interviews and describes **with humor** (!) the fake friendly attitude of those working in HR.

C.L. is 32 years old and is a graduate of medicine. He did the first internship in pediatric neuropsychiatry, but abandoned on account of the emergency room realities and **bullying**. Now he

is doing the internship in the Radiology specialty, a specialty in which he has more to do with technique than with people, which reduces the level of stress experienced.

B.M. - fresh graduate of the Faculty of Theology - is looking for a job. Now he continues his studies through a Masters in "Doctrine and Culture" within the same faculty and considers that a part-time job "in the area of helping people with disabilities foundations" is the optimal option for him. He is a volunteer in an association that supports TSA children, where he feels "very happy."

S.T. (the only woman in the group) is 34, she is a high school graduate and a call center operator. She is engaged to one of the group's members, whom she treats with the fun-loving attitude of a mother.

The interviews took place over several months, until July 2017, at the Faculty of Psychology, *Spiru Haret* University.

Have been addressed topics related to the diagnosis of their condition, how they lived their childhood, adolescence, friendship and love relationships, learning and work, the typical attitudes towards them, their needs and their hopes were approached. For members, the group also functioned as a support group, all of them considered the experience to be extremely enjoyable and useful.

These adults were diagnosed late, even if each of them felt at some point that he / she feels otherwise than others. For all, diagnosis came as a relief, awareness of their condition leading them to a better management of the situation and their own lives.

Since their first encounter with them, we have been struck by how authentic, unconventional thinking is, seeming to possess more degrees of freedom. Our atypical subjects, less socially like us, with a capacity to imitate limited, with a capacity more limited to decrypt paraverbal signals, do not suffer the same uniformity of the judgments we find among the typical (*By their nature, autistic people are rarely open to influences, their "fate" being isolated, and as originals*, - Oliver Sacks, 2017, p.269)

The conversation with them is stimulating, attractive, full of verve. There are people interested in „knowing for the sake of knowledge”, which makes it easier to introduce a new subject or to address new themes. As far as the themes of which they are deeply interested, they show great knowledge.

The most interesting aspect that comes out of the conversation with the participants in the support group is sincerity. It's not about knowing or lying, but lying to them is a matter too difficult to apply.

So, M.P states: *"In general, the values - let us say - moral, assumed, formed over time, noting that the deviation from this work is not working or is too" transparent "... it is so ineffective, that well, I do not lie. (...) I mean, it's the easiest thing to say the truth because if you lie, you have to make a game of chess too complicated: to put the lie in a position to be right with what the other thinks. That is, we need an already deeper processing that is not at hand!"*

C.P. thinks it's good *„to say things straight ahead (...) because it is just and logical"* is a fact from which it can not deviate even if it *"attracts unjust disciplinary sanctions."*

B. M. understands very well what lies and recognizes that, in order to live in society, *„small compromises are needed, especially those that have the task of covering up a trouble or an attempt"* – (the term "attempt" is used in the theological sense, with the meaning of suffering, trouble, difficulty passing one at a time - n.n.), but the lie *„by which you have to do evil that has negative effects on yourself or another, I can not say it."*

In turn, S.T. do not lie, because *„I do not understand the meaning of the lie. If a man knows you, he understands you and you do not have to lie."*

Closely related to the issues of authenticity and sincerity - having repercussions on social relationships, there is also the issue of compromise. For the typical individual, compromise is self-evident, being in many cases the key to survive in a group reliance or ascension.

M.P. says about himself: *„As age I feel anywhere from 5 years to 88 years. I have naivety like a child and habits, like an old man's rigidity.* ” These naiveties, due to the impossibility of reading the social contexts and the paraverbal, will seriously complicate the relationship, because M - although with a very high IQ - does not understand what is required in certain social contexts. Why is he asked for something and seems to expect something else (implied)? Why should he compliment someone, just because that's how they do? These problems are a result of the "the deficit in imitation, pragmatic language and theory of mind." (Dobrescu, I., 2010, p. 270).

About the difficulties in the decryption of the contexts, especially social, is also by tells us B.M.: *„When you are a normal person, you see reality naturally; when you are an autistic, you have to build a stone with stone. And so, stone with stone, I also build my image - not a reality - but a little subjective opinion.* ”

In an attempt to adapt to an unpredictable environment whose subtle signals decipher hard, most of them need rules. Where there is a clear, transparent rule and that they understand, they can work well.

Relationship with typics is indeed difficult. All adults with autism admit that they were - at least in childhood and adolescence - targets for harassment. Mannerisms in communication, stereotypes, adherence to routines, the bizarre of conduct, all of which made them rejected by the group, although they all wanted to be part of it, to be accepted.

Now things have changed to some extent. M.P. manages to impose through his intellectual abilities and broad interests. His speech is fascinating, as well as the mastery of various areas of knowledge. His speech is fascinating, as well as the mastery of various areas of knowledge. B and R were oriented towards a more tolerant environment (University of Theology), C is respected for his knowledge and - took refuge in a medical specialty where human interactions are smaller - he is successfully coping. S.T. manages to communicate collectively with some of his colleagues at work, and the need for relationship is satisfied by the group of people like her.

The same difficulties have been reported to me regarding the relationship with the opposite genre. With reference to the stereotype of the person with autism - incapable of emotional investment - it is false. Each of the group members was in love, but the difficulties in deciphering social signals, codes, and contexts discouraged them.

M.P. has unrealistic expectations from a relationship, dreaming of a partner who would replace his lack of social skills but also that of executive functions, being at the same time a good friend, but also an appropriate discussion partner.

B.M. misinterprets the signals received from possible partners and insists until it becomes inadequate, when it is inevitably rejected.

C.L., the most reserved of the group, admits that he was in love, but never confessed this feeling.

R.S. he understood that he was not successful at typical girls and managed to enter into a relationship that materialized (when we were writing these lines) in a marriage to S.T.

What we want to emphasize is that people with autism do not correspond to our representations in the sense that not posting or lack of emotional resonance impeding them from making friends or maintaining a couple relationship but the lack of means to properly interact, with neurotypicals.

They have to deal with the same issues in working relationships.

Although they all prove inclination to knowledge, they are avid seekers of information, true encyclopedias in certain areas (one of them is passionate about research and diagnostics, another in the IT field, the third one in spirituality, philosophy, religion, and finally M approaches what is the prototype of the autistic scientist with knowledge from various fields of knowledge: literature, spirituality), these skills do not guarantee professional success.

Two-way communication, the prevalence of informal rules over formal ones (in some environments), ambiguous messages, the unpredictability of each interaction, will - despite the sometimes exceptional, demonstrated skills - adults with autism can not really integrate among the neurotypicals.

An additional impediment is the existence of what we call *splintered skills* (Rhode, M; Klauber, T., 2004). Thus, M was reading the encyclopaedias at 5 years but could not tie his shoe, R does wonderful word games, but due to the lack of executive functions, he can not solve daily tasks that involve monitoring, planning, organization. C has exceptional capabilities of spatial representation and memorizing roadmaps and routes , but can never drive (as an expression of the executive's deficit).

As we have shown before, M has worked for 7 years as a university assistant. During this period he has demonstrated great pedagogical skills: *"I, as I was a student assistant, somehow managed to have a kind of system ... that I was attracting more interesting stories about the field of study. (...) I was pretty good to explain exactly what was supposed to be... because I had a little more of what my veteran teachers had quenched: consciousness or empathy about what it is like to be a student and how it is to not understand some things... to rip through, to dig through various resources until matter becomes clear. "*

C works as a medical intern at a Radiology department. He is pleased with the work he's doing at the hospital, saying that *„In Radiology, I have a huge set of assimilated information ... that stimulates me (intellectually)."*

B believes that a part-time job *„in the area of help for people with disabilities"* is the optimal option for him. He says he would like to help the others, just as he was, in turn, helped.

3. Conclusions and recommendations

We were interested in this subject not only from a theoretical perspective but also from a practical point of view.

Given that the prevalence of ASD (Budişteanu, M., Rad, F., Tudosie, V., Dobrescu, 2017) is 14% in the school population, we will have at most 10 years from now a population of young people and adults with autism whose members, recovered in various degrees but not adapted (the majority of whom) in the socio-professional contexts will only have the alternative of being inactive and draw invalidity pensions despite a huge potential that will remain untapped.

We dare to put forward some proposals for action, whose validity remains to be tested in practice.

3.1. The education system

First of all, our education system is not prepared (with few exceptions) to receive and educate atypical children, future atypical adults. One of the problems is that they are regarded as *broken* neurotypicals, which need to be repaired somehow, or they are otherwise composed - from the way they see and decrypt the environment, the way it behaves.

From our point of view, preferably an inclusive education in which we pretend to do (education, acceptance of differences, etc.), it would be more honest to create a special education, but actually adapted to the needs of these children.

Obviously, given the enormous behavioral variability and the different levels of operation, it should be conceived of graded and types of disability (and this should not be understood as a disguise, but rather as a respect for these differences).

The curriculum could be truly adapted to meet their needs and teachers should specialize in a certain type of didactics of teaching, based on the profound understanding of the condition to which it addresses and its particularities. The learning environment should also be adapted.

For older ages (starting with preadolescence), we plead for introducing psychological assessments to identify children's special skills so that professional guidance can be started.

3.2.Sensitization of employees

Another aspect worthy of consideration is **lobbying among potential employers** - as well as **borrowing ideas for good practices**, models, projects with and for young people with autism from countries already having such concerns.

In this regard, a project of the *Sposa Society for the Help of People with Autism* (Czech Republic) can serve as a model: on the one hand, the skills of young people with autism are identified, they are trained through programs to develop the identified skills, then identified potential employers, explaining the strengths of these people and how to work with them to achieve optimum results beneficial to both the employer and the employee.

3.3.Campaigns dedicated to adults with ASD

In recent years, more and more media campaigns have aimed to raise public awareness of the existence of ASD in children, and countless fundraising campaigns to support the therapy of these children were deployed.

We do not know yet a campaign to look at the young / adult with autism, as there are too few centers, associations or foundations dedicated to working with them. At a time when autism is a condition of life, not a disease (so it does not heal), this category is totally ignored.

In addition, since many of the changes in a society start from the categories directly concerned, it may be appropriate to work with parents' associations, acting as a coherent body, by setting up long-term strategies that, at a this moment could be brought to the political decision-makers to turn into public policies.

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