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Perspectives
on Autistic Spectrum Disorder

a cura di
Loredana Al Ghazi, Tamara Zappaterra

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Summary

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THEORETICAL ASPECTS OF AUTISM SPECTRUM DISORDERS

Second part
ASPECTS OF DEVELOPMENT, INTERVENTION METHODOLOGIES, RESEARCHES ON AUTISM

Third part
STUDIES ON AUTISM SPECTRUM DISORDER FROM NATIONAL CONTEXTS

Foreword

Loredana Al Ghazi, Tamara Zappaterra

This book represents one of the intellectual outputs of the European project "Innovative Academic Course on Integrative Interventions for Children with Autism Spectrum Disorders - IACIIC-ASD" (KA2 – Cooperation for Innovation and the Exchange of Good Practices – KA203 Stratetic Partnership for Higher Education), which lasted from November 2017 to November 2019 (and its publication is funded by the Erasmus + Programme).

The coordinator of the project was the West University of Timisoara (Romania), and the partners were the Sveuciliste u Zabrebu Educacijsko-Rehabilitacijski Acijski Facultet (Croatia), and "Lucian Blaga" University of Sibiu (Romania) and Università degli Studi di Firenze (Italy). Università degli Studi di Firenze was also the leading organisation for this output.

Autism Spectrum Disorder (ASD) refers to a group of complex neurodevelopmental disorders characterized by repetitive and specific patterns of behavior and difficulties with social communication and interaction (APA, 2013). At international level, the theme of ASD has received particular attention in recent years from the point of view of educational policies and educational institutions, from which the need to take stock of this issue at European level. According to the Higher Education Reform the partnership proposed an innovative approach to the ASD, that enhanced the quality and relevance of student's knowledge and skills in the field. This not only enrich the curricular offer of partner Universities, but also respond to a specific need will increase the number of qualified and high-skilled graduates who will work with children wit ASD and their families. The four Universities jointly delivered a Course in a blended manner (face-to-face and via an online platoform), and the students from tree different countries (Romania, Italy, Croatia) gained acces to a set of activities supported by ITC, in line with the EU policy paper on Rethinking Education.

The book is structured in three parts: the first one is theoretical, the second one includes contributions concerning specific aspects of ASD, and the third gathers some studies emphasizing the national contexts.

First part

Theoretical Aspects of Autism Spectrum Disorders

From *schizoid psychopathy* to a *natural human variation*
Deconstructing autism[1]

Loredana Al Ghazi[2]

I. The past

1. *A little bit of history*

Nothing exists until it has a name[3]

Kanner once said "I never discovered autism; it was always there" (Silberman, 2015: 188). Hundred years before Kanner's seminal articles, published in 1943-1944, that marked "the birth of autism", we can find livresque accounts of what now we call *autistic features* and *autistic people* (for more, see Donvan & Zucker, 2016; Silberman, 2015; Fitzgerald, 2019) descriptions of historical or fictional figures]. If we can ignore these records as non-scientific, we can not overlook all the journal-published articles before 1943 in wich autistic traits were described, before they were folded into the umbrella of a syndrome:

- in 1926, Grunia Sukhareva reported "a detailed description of autistic traits in children in the *Monatsschrift für Psychiatrie und Neurologie*" (Manouilenko & Bejerot, 2015: 1761) in 6 cases she observed for two years, in Moscow, at Psychoneurological Department for Children. She used the label *schizoid psychopathy*, in order to differentiate from *schizophrenia*, being aware that in children,

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[1] With reference to: *Constructing autism* (2005), a book by Majia Holmer Nadesan and *Deconstructing Harry*, a movie by Woody Allen. Harry remembers events from his past and scenes from his best-selling books as characters, real and fictional, tryng to understand what makes him the way he is now.

[2] West University of Timişoara, The University Clinic for Therapies and Psycho-pedagogical Counselling.

[3] A quote by Lorna Wing, a pioneer in the field of childhood developmental disorders who advanced understanding of autism worldwide, introduced the term Asperger syndrome in 1976; and founded the National Autistic Society (NAS) in the UK; considered to be the architect of the spectrum model of autism; mother of an autistic daughter (Wikipedia).

“the clinical picture shares certain features with schizophrenia, but which yet differs profoundly from schizophrenia” (Wolff, 1996: 131). The article appeared initially in Russian (1925), and the English translation appeared only in 1996 (Wolff, 1996).

- in 1935, Anni Weiss published *in American Journal of Orthopsychiatry* the case of Gottfried, a boy she consulted while she was working at the University Children’s Clinic in Vienna (Weiss, 1935);
- in 1938, Hans Asperger gave the first public lecture on autism at the University Hospital in Vienna, published in *Wiener Klinische Wochenschrift* (archive stored in Johns Hopkins University Library) (Czeck, 2018). He used the term autistic to label the self-withdrawn, one of Bleuler’s four putative fundamental disturbances characteristic of schizophrenia. Feinstein (2010: 11) citing Maria Asperger Felder (2008), Asperger’s daughter, evokes a letter sent by Asperger to one colleague in 1934, where he points on “the difficulties of diagnostic concepts and suggests the possibility that ‘autistic’ might be a useful term”.
- in 1943, Kanner reported 11 cases in his article *Autistic disturbances of affective contact* in the American journal *Nervous Child* (Kanner, 1943).
- in 1944, Asperger presented 4 cases in “*The ‘Autistic Psychopaths’ in Childhood*” *(“Die ‘Autistischen Psychopathen’ im Kindesalter”)*, in *Archiv fur Psychiatrie und Nervenkrankheiten* (Asperger, 1991; Wing, 1981). As in Suckarevas case, the paper was brought to the attention of the English-speaking world many years later (Van Krevelen 1962, 1971; Wing, 1981). Also, in 1944, Kanner coines the term *infantile autism* in his second groudbreaking article *Early infantile autism* (Kanner, 1944).

Kanner was certainly not the first one to describe the clinical picture of autism, nor the first who had the idea to label the features as autistic (borrowing the term from Bleuler), but he was the first to publish a paper that contained both the description of the autistic features and the label for them (Donvan & Zucker, 2016; Feinstein, 2010; Silberman, 2015). So, 75 years ago, the official story of autism begins, and for decades Kanner was viewed as “the father of autism”. Kanner repeatedly said that it was for the first time, in 1943, that such cases were ever described in the literature: “some children whose condition differs so markedly and uniquely from anything reported so far” (Kanner, 1943: 217). Although he emphasized the uniqueness of the condition and the difference from schizophrenia, other authors assumed that the two conditions were not so different. Kanner's colleague, psychiatrist Louise Despert, was contrariety by his statement, replying: "Had he not been reading my papers?" (Silberman, 2015: 124). In a response article she wrote> "It seems to me that the greatest contribution this article is making is in its thorough, accurate, and illuminating description of clinical cases", … "However, if you will permit me to say so, I object to the coining of new terminology for entities which, if not so carefully described, have been previously reported" (for more on childhood schizoprhrenia see Potter, 1933; Despert, 1938; Bender, 1941; Fitzgerald, 2019).

2. *The diagnosis*

You shall be called by a new name…[4]

"The new terminology" was necessary despite Despert's opinion, for the simple reason that a new pathology was decelled. Since Suchareva, Asperger and Kanner's first descriptions, the diagnosis has undergone multiple modifications informed by research and clinical work conducted over the next several decades. As longitudinal and other data appeared it was made clear that autism formed a distinct diagnostic category. It took decades from the first published articles, for the American Psychiatric Association to introduce autism in the Bible of American psychiatrists-Diagnostic and Statistical Manual of Mental Disorders[5].

Right in the first edition of DSM (DSM-I, 1952), autism was present under the name of "schizophrenic reaction, childhood type". According to APA, the use of the term "reaction" throughout DSM "reflected the influence of Adolf Meyer's psychobiological view that mental disorders represented reactions of the personality to psychological, social, and biological factors" (APA, n.d.-b). DSM failed to provide a definition of autism, indicating more what this condition *is not* rather than what *it is*: "The clinical picture may differ from

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[4] A quote from the Bible "You shall be called by a new name which the mouth of the Lord shall designate" (Isaiah 62:2). Christian designate themselves by all kinds of names which the mouth of the Lord did not name.

[5] We will refer further at the Diagnostic and Statistical Manual of Mental Disorders released by The American Psychiatric Association's (APA) and not to International Classification of Diseases (ICD) which is the global standard for diagnostic health information, for the reason that first appearance of autism (although not under the name of autism) was in the DSM and only years later in the 8th edition of ICD) under the label of Infantile autism (ICD-8, 1967).

schizophrenic reactions occurring in other age periods because of the immaturity and plasticity of the patient at the time of onset of the reaction" (Silberman, 2015: 237). Of course, autism and schizophrenia, are in part, overlapping conditions, but even for Suchareva, 45 years earlier, it was clear that they differ a lot. The autism in DSM-I was less than Suckareva's description but close to Despert opinions.

The second edition of DSM (DSM-II, 1968) published 16 years later was not much better, citing "autistic, atypical and withdrawn behavior", "general unevenness", "failure to develop identity separate from the mother's" (for more see Silberman, 2015: Chapter X, *Pandora's box*). We are in the sixties, right in the middle of an epoque when mothers were blamed for their children's disorder. Since Kanner first article on autism, more and more cases were detected, but the cause of autism remained unknown and medication ineffective (for more, see Loretta Bender on electric shock therapy and antipsychotic medication [Bender, 1960] used to treat autism).

As early as 1948, The Times Magazine headlined *Medicine: Frosted Children*, inducing the idea that "diaper-aged schizoids", "happiest when left alone" are the products of cold parents that are "freezing their children" into autism. Kanner postulated from the beginning that autism was innate (surprisingly, as he never observed babies, just one child below the age of three when Kanner, the other ten children in his report were between the ages of 3 and 14 years). A sad metaphor was born then- "the refrigerator mother", a mother incapable to offer love and nurture her child. The author of this metaphor was no other than Leo Kanner. (Donvan & Zucker, 2016; Silberman, 2015). 20 years after the Times Magazine article, the second edition of DSM seems to follow the same line. This time, not Kanner but Bruno Bethelheim is the primadonna singing the tragic aria of a mother punished with an autistic child for the guilt of not wanting to be a mother.

Bettelheim's guess that 'the precipitating factor in infantile autism is the parent's wish that his child should not exist' (Finn, 1997). As director of Orthogenic School at the University of Chicago, a residential treatment center, he believed is better for such children to undergo a "parentectomy", a separation of children from their parents for extended periods of time (Gardner, 2000). Bethelheim's book, *The empty fortress*, published in 1967 was a great success. The same year, Clara Clairborne Park published *The Siege* (1967), a sensitive and touching memoir of raising an autistic daughter. She failed to take the empty fortress under the siege in the public or professionals' eye.

The psychoanalytical (Roser, 1996) pseudo-scientific (Herbert, Sharp & Brandon, 2002) bettlheimian theory on autism etiology even shadowed Bernard Rimland's theory, which emphasized the neurological aspects of Infantile *Autism: The Syndrome and Its Implications for a Neural Theory of Behavior* (Rimland, 1964).

The third edition of DSM, was released in 1980. It was the moment when psychoanalytical was dismissed as ethiology and Kanner's infantile autism syndrome was finally recognized as a diagnosis distinct from schizophrenia> "pervasive developmental disorder". DSM_III listed specific criteria required for a diagnosis (occurring in the first 30 months of life). But then, DSM-III was revised in 1987 (DSM-III-R) and it seems that "autism had been transformed into something that Kanner would have barely recognized" (Silberman, 2015: 151; 424). This is because DSM-III-R recognized the heterogeneity of the disorder and broadened the conceptualization of autism (Volkmar, Bregman, Cohen & Cicchetti, 1988). This approach differs from that used in DSM-IIl, which was closer of Kanner view of autism as monolithic, tending to emphasize a narrower and more specific diagnostic concept. DSM-III-R gave us a first glimpse of autism as a spectrum.

In 1994, in the fourth edition of DSM (1994), APA introduced the Asperger syndrome, two years after its inclusion as a standard diagnosis in the 10th edition of the World Health Organization's diagnostic manual, International Classification of Diseases (ICD-10).

Finally, both views on autism-Kanner and Asperger-get their recognition as separate diagnoses. Although both labeled their cases "autistic," they observed different populations of children, so the conditions they described diverged in many respects. Both insisted on the differences between the, until the very end: Asperger considered his syndrome to be different from Kanner's (Donvan & Zucker, 2016: 241 citing Wing, 1981). Also, Kanner considered that Asperger syndrome "if at all related to infantile autism, is at best a 42nd cousin" (Silberman, 2015: 140 citing Kanner, 1970).

Lorna Wing reflected on her work and her victory of seeing the Asperger Syndrome recognized as a standalone diagnosis and she was not convinced that her success it was necessarily a positive development for the domain: "I wish I hadn't done it. I would like to throw all labels away today, including Asperger's syndrome, and move towards the dimensional approach. Labels don't mean anything, because you can get such a wide variety of profilessome people are brilliant at mathematics but get pleasure rocking back and forth twiddling their hands.The trouble is that it would be very hard to make an international system based on profiles. Human beings seem to need categories" (Feinstein, 2010: 000). She admitted "Since the publication of my paper on Asperger, I have felt like Pandora after she opened the box" (Fitzgerald, 2017: 16).

What was the effect of DSM (III-IV) categorization? The diagnosis is put based on symptoms and the patient must meet a minimum number of criteria to be diagnosed. Somehow it seems like a circular logic: How is a person diagnosed with autism? Because he has the symptoms of autism. Why is he having symptoms? Because he has autism. We cannot rely on lab or imagistic techniques to identify biomarkers in case of autism. Autism can be diagnosed only through clinical interviews, observation, and secondary reports from parents. Allen Frances, Chair of the DSM-IV Task Force once said "Nice someone understands what DSM is/what it isn't. Mental disorders are constructs, not diseases. Descriptive, not explanatory. Helpful in communication/treatment planning, but no claims re causality/homogeneity/clear boundaries. We wrote this in DSM-IV Intro but no one read it" (Shedler, 2019).

The fifth and last edition of DSM (DSM-5, 2013) eliminated Kanner and Asperger syndromes as separate diagnoses. Both syndromes were included in the spectrum model anticipated by Lorna Wing, while Childhood disintegrative disorder and Rett syndrome were removed from the autism category. Sukareva's work remained unknown although she described autistic features two decades before Kanner and Asperger. More than that, she was very close to the criteria listed in the fifth edition of DSM. Manouilenko, a psychiatrist in Stockholm compared DSM-5's criteria to Sukhareva's observations and the result was impressive: DSM-5 describes ASD consisting in social deficits- Sukhareva, as a "flattened affective life", "lack of facial expressiveness and expressive movements" and "keeping apart from their peers"; DSM-5 list stereotyped or repetitive behaviors, restricted interests and sensory sensitivities- Sukhareva described as "talking in stereotypic ways," with "strong interests pursued exclusively" and "sensitivities to specific noises or smells" (Manouilenko & Bejerot, 2015b).

II. The present

1. *ASD- the disorder*

I need a doctor
Call me a doctor…[6]

The medical model was for a long time the solely proposed to explain autism and it is no wonder since the pioneers of autism were all psychiatrists. It is easy to understand that they saw autism as an illness that must be treated. Even nowadays, autism is still regarded as a disorder by many health professionals and parents who stick to the deficit-based characterizations of autism. The parents say "there is something wrong with my child, doctor!", they ask for treatments, for prescriptions… But in autism case it is not the case! Right after the diagnosis, the parents will find out there is no cure for autism. In psychiatric terms, based on the classical theory in psychopathology (Leonhard, 1976) we maid say that autism is a psychosis due to the poor contact of autistic people with reality. French psychiatrists, most of them representing the psychoanalytical school, still stand by the definition of autism as psychosis or disease. Even if they are served with the argument that autistic people do have a "lack of contact with reality" or a 'lack of order or intelligible pattern' (Baron-Cohen, 2017) but do not experience delusions or hallucinations, they reply with the question: then why the psychiatrists are the ones called to put a diagnosis? why the Americans keep it in their "manual of mental disorders"? Maybe the answer is that, maintaining the autism "in the manual", is in benefit of both patients and practitioners. Coding autism as a disorder, allow facilitating communication between professionals so they can manage and justify the coverage for interventions and services (Beck, 2018). One of the aims of the standardization of symptomatology was also to facilitate the development of effective forms of interventions. On the other hand, there are voices who condemn creating fixed disease categories, claiming that this is the way psychiatry attempts to legitimize itself through rigid adherence to the biomedical model that illnesses are stable entities (Leveto, 2018).

A recent study finds that psychiatric diagnoses DSM-5 are "scientifically meaningless". The researchers conclude that there is "a huge amount of overlap in symptoms between diagnoses"; "diagnoses tell us

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[6] The title of a rap song by Dr. Dre featuring Eminem, calling for the doctor as the solution for his mental disorder.

little about the individual patient and what treatment they need", and "trauma has a limited causal role in, despite research evidence to the contrary" (Allsopp, Read, Corcoran & Kinderman, 2019). Except of trauma (because still there is no proof that early exposure to any kind of trauma can play a role in later developing specific autistic symptoms), this can be the case of autism too. More and more voices raise recently against bio-medical model for explaining mental disorders by creating fixed disease categories, arguing that "pragmatic criteria may give clinical flexibility but undermine the diagnostic model". Still, we need the diagnosis to provide the services that people on the spectrum need. Sometimes, at least în Romania this is the case, the diagnostic is "negotiated" in order to permit the access to free services, interventions or medication (note: drugs are not administrated for autism, but for co-occurring conditions).

It is quite a paradox that in the same time, in the doctor's office, a parent insists for a diagnosis and a cure, but in a different context (kindergarten, school, playground, etc.) the same parent claims that his child is just different., no lesser than the neurotypical children. It is a matter of *sameness* and *difference*, we will discuss later.

But it is also easy to understand why the parents are playing this card: with all the progress, autism has no cure for the moment, as the causes are still unknown. Decades ago, people on the spectrum were seen as being "mentally ill". The individual/medical/deficit model, posit that all problems and challenges faced by an autistic person is their own, because they are "deficient" in some area (such as the people that don't have or lost their sense of hearing or vision. Impairment was viewed as an illness). In some cases, the "illness" can be cured: the sight, the hearing, the mobility, even the mental health can be totally, or to some extent, restored trough surgical interventions, prosthetics, medication, and so on… One of our studies (Al Ghazi et al., in press) concluded among others that all the parents that received the diagnosis for their children want to "get rid of autism". They hope for a complete recovery from autism, especially if they find in the media and literature about the children "who escaped autism". There are some well-documented accounts of "autism recovery" (in Romania, the most notorious case is Radu[7]), by "recovery" understanding the level where we can not distinguish anymore the autistic persons from their peers. They hope for a cure to be discovered in the future, they are willing to try all kinds of treatments (sometimes pseudoscien-

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[7] See the next chapter "ABA. The Romanian story".

tific new treatments or harmful combination of interventions). From this point of view, those parents are totally immersed in the medical model. When it comes to autistic persons' rights and the way the society responds to their requirements, we believe that the social model of disability suits them better and we will further present some aspects of this model.

2. *ASD- the disability*

> I don't need no doctor
> 'Cause I know what's ailing me…[8]

Over the years, some interventions were developed in order to help people with autism (and their families) to have at least a better life quality if not being productive and have a social successful life. Even if they will reach the final destination of recovery from autism, on the road to it, a lot of support and empathy are needed. If autism is not to be seen as a medical condition needed to be cured or prevented (Barnes et al., 1999; Charlton, 1998), then it can be regarded as a disability. The disability rights movement strongly opposed to embedding disability into the medical model arguing this "can be deeply dehumanizing" and "can evoke unwanted pity" (Oliver, 1990; Williams, 1996). The social model of disability asserts that a person is only in part disable due to his own condition and in part, the disability is created by the way that society understands to respond to their specific needs. In the case of autism, as the proponents of disability movement sustain, instead of trying to make autistic people to adapt to our world by forcing social interaction and communication and by reducing their restricted and repetitive behavior, maybe we can create the proper context for them to develop and flourish.

We all have our strengths and difficulties in some areas and show disability in others. Not everybody is able to sing or to dance, many of us are tone-deaf, so in a choir or on the dance floor we are to be seen as disabled. There is a metaphor of the fish required to climb a tree, attributed to Einstein, often quoted by the supporters of the social model of disability. Expanding on it, someone said about people on the spectrum: "We are freshwater fish in saltwater. Put us in freshwater and we are fine. Put us in saltwater and we struggle to

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[8] The title of a Ray Charles song about the comfort that love and understanding can provide.

survive". Are we the "saltwater creatures" that are disturbed by those coming from the "freshwater"? Can we desalinate part of our water so we can include and integrate autistic people? And if we are doing so, it is for them (because they ask and we can do this) or it is for us too- for they can enrich our world with their gifts? (for more on "desalination" or deinstitutionalization see Chapter 4: *Education*, Chapter 5: *Before, Outside, and After the Classroom* [Pitney, 2015] and Chapter 4: *Autism Education and the Illusions of Inclusion*, Chapter 5: *Educating Youth With ASDs for Their Future* [Siegel, 2018]). Kanner wrote: "The study of the natural history of human development, its deviations, and treatment is a ramified, objective, pluralistic, relativistic, and melioristic science. In its present state, and hopefully in the future, such study will be what I like to call a science dunked in the milk of human kindness" (Kanner, 1976). We believe that human kindness played a great role in shifting the paradigm from seeing the autistic people as deficient (having a condition that should be eradicated or, if possible, prevented (Barnes et al., 1999; Charlton, 1998) to a softer approach through the lenses of the social model of disability.

In a world of flowers, Armstrong imagined the following dialog between the doctors and their flower-patients:

> Visualize a gigantic sunflower coming into the rose psychiatrist's office. The psychiatrist pulls out its diagnostic tools and in a matter of a half hour or so has come up with a diagnosis: "You suffer from hugism. It's a treatable condition if caught early enough, but alas, there's not too much we can do for you at this point in your development. We do however have some strategies that can help you learn to cope with your disorder" […] Next on the doctor's schedule is a tiny bluet. The rose psychiatrist gives the bluet a few diagnostic tests and a full physical examination. Then it renders its judgment: 'Sorry Bluet, but you have GD, or growing disability. We think it's genetic. However, you needn't worry. With appropriate treatment, you can learn to live a productive and successful life in a plot of well-drained sandy loam somewhere.' Finally, a calla lily enters the consulting room […]: "You have PDD, or petal deficit disorder. This can be controlled, though not cured, with a specially designed formula" (Armstrong, 2010: 12).

What would be like "to treat" all the flowers until they will all have the correct dimensions, the right form, the proper scent? Maybe it is our power to cease to cultivate flowers that do not fit in our model, maybe it is possible to graft the species that do not correspond to our garden design, but maybe we can also change our views and see the beauty of diversity and accept that some varieties of "plants" come in different shapes and colors, not for spoiling the symmetry of our garden, but to make a difference. We presented this metaphor as an introduction for the third and most recent approach of autism – the neurodiversity – where autism is regarded not as a medical condition or disability, but as difference.

3. *ASD- the difference*

Call me by your name[9].

Neurodiversity originated as a movement among individuals labeled with autism spectrum disorders who wanted to be seen as different, not disabled or ill. As early as 1997, Harvey Blume wrote for the NYTimes:

> Yet, in trying to come to terms with an NT [neurotypical]-dominated world, autistics are neither willing nor able to give up their own customs. Instead, they are proposing a new social compact, one emphasizing neurological pluralism. […] The consensus emerging from the Internet forums and Web sites where autistics congregate […] is that NT is only one of many neurological configurations – the dominant one certainly, but not necessarily the best (Blume, 1997).

However, even if Blume was the first to write about neurological pluralism and autism as difference, it is Judy Singer (an Australian sociologist, a person on the spectrum herself and the mother of a girl with Asperger) who is credited with the coinage of the term *neurodiversity*. Her 1998 honors thesis title was "*Odd people in: the birth of community amongst people on the Autistic Spectrum: a personal exploration of a new social movement based on neurological diversity*". A few months later, Singer's work was published in the UK as a chapter in *Disability Discourse* (Corker & French, 1999: 64). The title was "*Why Can't You Be Normal for Once in Your Life?*" – "an expression of frustration heard almost daily in Singer's family…" (Craft, n.d.). The title deserves attention for the fact that the neurodiversity proponents eschew negative language such as "abnormal", "disorder", "deficit", "impairment", and receive autism as a way of being. The

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[9] The title of a movie by Luca Guadagnino based on the acclaimed novel by André Aciman, a sensual and transcendent tale of the first love of a 17-year-old young man with a 7 years older man. They hide their love, not knowing if their love will be accepted by their families and society. With reference to the parallel made by neurodiversity supporters and gay pride.

way we call or address to autistic persons, the way we use language to describe autism, seems to have a strong impact on shaping people's perception of it (Kenny et al., 2016). The first large-scale study which examined the terms that UK community members use to describe autism (commissioned by the UK National Autistic Society) showed that there is not one single accepted term used when talking about autistic people. We use terms like "autistic person", "person with autism", "on the autism spectrum' or simply "people on the spectrum"[10]. Using of person-first language[11] is not necessary intrinsic negative (Halmari, 2011). Jim Sinclair (1999), autism activist, affirms that an autistic person can never, and should never attempt to, be separated from their autism. Also, avoiding to use person-first language, referring to a person with autism, instead of identity-based language, placing positive in front of nouns, is not implying that autism is intrinsically negative. In the public discourse, in Romania, calling other people autistic when they are not, seems to be a greater offense for autistic people or autistic children's parents than for the nonautistic person to whom the words were addressed[12]. We argue that more important than the way we label autism is what we can and must do for them. Judy Rapoport senior child psychiatrist and a former chief of child psychiatry at the National Institutes of Mental Health NIMH, told, the anthropologist-sociologist Roy Richard Grinker, in a 2007 conversation quoted in In a different Key: "I am incredibly disciplined in the diagnostic classifications in my research, but in my private practice, I'll call a kid a zebra if it will get him the educational services I think he needs". (Donvan & Zucker, 2015). But what if they do not want "to be helped"? Neurodiversity rejects the idea of "cure" (Ortega, 2009). While autism activism fights for more money invested in

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[10] "The term – on the autism spectrum – was preferred by significant numbers of autistic adults (45%), parents (38%), family members/friends (48%) and especially professionals (60%). The term 'autistic' was endorsed by a large percentage of autistic adults, family members/friends and parents but by considerably fewer professionals; 'person with autism' was endorsed by almost half of professionals but by fewer autistic adults and parents" (p. 446).

[11] Language that refers to people first as individuals and then to their disability only if necessary (Bailey, 1991; Blaska, 1993). Terms such as 'disabled person' and 'the disabled' were held to give undue prominence to the disability and to equate a person completely with their disability.

[12] The Romanian PM asked public apologies for labeling some politicians autistic: "I believe these people are autistic and do not see and hear what is visible to all people of good faith", she said. The Association of Parents of Children with Autism reacted by an open letter and the National Council for Combating Discrimination was notified.

research for therapies, treatments, finding the cause of autism, identifying biomarkers (as early as possible, through prenatal tests), the autistic activism is focused on acceptance of autism as a way of being. For instance, a successful intervention that can eliminate flapping, or will establish a sustained eye contact, or facilitate the acceptance of being touched and hugged (things that many parents especially wish from their autistic children) is seen invasive and even unethical (for more see the affidavit of Michelle Dawson's and her intervention at the Supreme Court of Canada against ABA on http://www.sentex.net/~nexus23/naa_sup.html).

Orsini (2012) quoting Silverman (2011) touched a sensitive point when described autistic people as "characteristically dependent upon the goodwill or benevolence of others, whether they are sympathetic policymakers who have been touched by autism or the loving parents and caring friends who perform much of the emotional labour that autism requires".

The neurodiversity proponents fight for rights, identity, and autistic culture more than for governmental support, coverage for services, etc. They claim that, from a political standpoint, differences in brain structure and neurological functioning have no more significance than differences in race or gender (Singer, n.d.). Craft quoting Singer: "For me, the key significance of the Autism Spectrum lies in its call for and anticipation of a politics of neurological diversity, or neurodiversity. The neurologically different represent a new addition to the familiar political categories of class/gender/race and will augment the insights of the social model of disability". (Craft, n.d.). While the concepts of disability and neurodiversity are not incompatible, the concepts of disorder and neurodiversity are. Maybe the most poignant critique to neurodiversity is based on individuals with autism who have intellectual disability, limited communication skills, co-occurring conditions. 75% of autistic people also have intellectual disabilities and sensory difficulties, while others are high-functioning. Jaarsma and Welin show that "the broad version of the neurodiversity claim, covering low-functioning as well as high-functioning autism, is problematic. Only a narrow conception of neurodiversity, referring exclusively to high-functioning autists, is reasonable" (Jaarsma & Welin, 2012: 20). The authors conclude that "a psychiatric defect-based diagnosis" could harm these people in the sense of pathologizing their existence, while for the others the neurodiversity inclusion could mean the cancellation of their passport that permits them to access existing or future treatments, medication, and interventions.

We also fully subscribe to a narrow concept of neurodiversity, as well as fully concur with Baron-Cohen recent position on the matter:

> "Disorder," "disability," "difference" and "disease" being applicable to different forms of autism or to the co-occurring conditions. Neurodiversity is a fact of nature; our brains are all different. So there is no point in being a neurodiversity denier, any more than being a biodiversity denier. But by taking a fine-grained look at the heterogeneity within autism we can see how sometimes the neurodiversity model fits autism very well, and that sometimes the disorder/medical model is a better explanation (Baron-Cohen, 2019).

Echoing the same author, considering autism as a different cognitive style, rather than deficient, could mean that receiving the diagnosis of high-functioning autism would be like finding your child is left-handed (Baron-Cohen, 2000) or gay. But gay people, left-handed, do not need services and intervention designed and implemented specifically for them, they do not cost society, they are productive people. When promoting autistic pride, many examples of successful past or present figures appear: they are artists, writers, researchers… When they talk about their accomplishments, they mention their differently wired brain, and autism is viewed as a gift. Although it is impossible to prove that the correlation between achievements and the presence of autism means that autism is the cause. It would be like saying that a great fashion designer made history in haute couture because he is gay. Both neurodiversity and gay movements rely on "the corporeal difference" (differently wired brains, homosexual bodies)-they are distinct from others, but no less valuable than neurotypical or straight people. So they are simultaneously claiming that neurodiverse and neurotypical are both "the same and different" (Runswick-Cole, 2014). Continuing the analogy, it is shown that homosexuality also was viewed as a disorder until it was decided that the challenges that homosexuals faced were the outcome of social conditions rather than an inherent feature of a disorder, the main problem being that gay people did not fit to the "heterosexual and biological norm" (Richardson, 2005). Similarly, many autists could have psychiatric and psychological problems due to the autism policy character of present society (Jaarsma & Welin, 2012). So, from the neurodiversity viewpoint, if autism will be regarded as a natural human variation, many of the problems that autistic people face will fade. Considering autism as a form of diversity of human minds (Armstrong, 2010; Feinstein, 2010; Silberman, 2015; Donvan & Zucker, 2016; Baron-Cohen, 2017) will lead to the removal of disorder-stigma and thus more of the autistic persons (and those close to them) will embrace autism as a part of their identity. Being autistic must give them a sense of belonging to a community where they see themselves proud to be in and advocate for their rights (Singer, 1999) (Bagatell, 2010). It was a matter of identity too in other movements (black, women, disabled, gay, civil rights…) which conducted to important changes in our society.

But not all the members of the community consider autism to be an aspect of their identity (Davidson & Henderson, 2010). A mother told me once: "I have had cancer a few years ago. I fought cancer and, at the same time, I also fought for my rights and other people's rights to a proper treatment that in Romania was not available for us. I never thought about myself as "cancerous". I refused to accept cancer as a part of me, it was never mine, "my cancer"! It was something that made me ill for a period of time- it came and go. And I think it is the same as my daughter's autism. She was not born autistic, as I was not born cancerous. She was a normal child for the first and a half years of her life. Then something happened and she lost her smile, her joy…she was like trapped into something and we could never reach her anymore. But I hope I will get my child back someday. Till then, I fight with all my strength for her rights, education, integration and so on…". So, not everyone endorses the idea that autism is part of them or their child's identity. Many community members face challenges they or their children confront and thus they advocate for new ways to treat, cure, or prevent autism. It was not a lack of information or ignorance that made that mother to affirm that she was not born with cancer or her daughter with autism. She was fully aware of the fact that cancer or autism could be "written in their genes". But she also believed that "something can be done", that it is not "everything about the genes", that it is a lot that we can do in order to switch the way "we are programmed to develop a tumor" or "differently brain-wired" in order to exhibit autistic features. So, we can see there are two different perspectives that not necessarily divide the community (Baron-Cohen, 2019) but also not necessarily cooperate (Leveto, 2018): the autism rights movement (which resembles a lot with the disability rights movement) and the neurodiversity movement. Orsini (2012) distinguished between *autism* and *autistic* activism (the rights, recognition of identity, autistic culture and acceptance of autism as neurological difference). Some parents, adult autistic persons and professionals connected to the field advocate for the rights of access to intervention supported by the government or insurance companies, while others consider that it is a violation of the autistic persons to be treated, not to be let the way they were meant to be but forced to adapt and being "normalized". These issues were brought even to court in an attempt to obtain a legal backing either for refusing to accept the therapy (Ortega, 2009), either for the right to access therapy[13] (Orsini, 2012).

III. The future

What is it like to be a bat?

There is a notorious question asked by philosopher Thomas Nagel (1974) "What is it like to be a bat?". Echoing Nagel we can ask: "what it is like to have autism or being autistic?". Nagel explains that before we can define what it is like to be a bat, we must develop a method that can discern between the observed characteristics (third-person attributes) and the subjective state (first-person attributes). It was suggested that (Pitney, 2015; Skubby, 2017) medical professionals are "far from being thoroughly knowledgeable" about autism, in fact, autistic people being in the position "to possess knowledge of their condition". Parnas, Sass and Zahavi (2013: 76, quoted by Beck, 2018) affirm that, for example, the structured interview used by psychiatrists, psychologists, educators are "unable to capture the subtle forms of experience and expression that constitute the essential psychiatric object". Taking such insights into consideration, the conclusion should be that any attempt by neurotypicals to define autism fails. We can accept that the high functional autistic people could better describe the condition, in the same way that a doctor could better understand, describe and research diabetes, alcoholism, depression if he is a diabetic, alcoholic, depressed himself (although it contrast with the author preference of a phenomenological attitude that requires to bracket our own experience and let us be surprised by and opened to what other may bring). But again, the same nagelian question can be asked: can a high-functional autist answer what is like to be low-functioning or profound autistic?

The well-known motto "Nothing about us without us" was transposed in "By autistics for autistics". The challenge of representing autistic persons "is not resolved, however, by a simple recourse to this organizing principle" (Orsini, 2012: 815).

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[13] Auton v. British Columbia.

Look what they done to my song…[14]

Firzgerald (2019) predicts that the future of psychiatry will be neurodevelopmental and that the neurodevelopmental spectrum is far wider and far more important than suggested by DSM 5. At the launch of DSM-5, APA called it a "living document" that would live primarily online. Some updates appeared since its publication in 2013 but, to our knowledge, there are no planned revisions to the DSM for the moment. In the ICD-11, autism criteria moved to a new, dedicated 'Autism Spectrum Disorder' section which mirrors the DSM-5's criteria. The ICD-11 also makes a distinction between autism with and without intellectual disability and highlights the fact that older individuals and women sometimes can mask their autism traits. In our opinion, as long as we remain at a descriptive level, a new edition of any manual or classification would be like redecorating and invite guests to a "new house" which is actually the same house. Moving into a new house (or at least building a new floor or outbuildings to the existing edifice) means to shift from descriptive to explanatory. With all the progress in neuroscience, genetics, and brain scanning we still can not understand the causes of autism. At least, the future seems promising in establishing the diagnosis based on biomarkers (Howsmon et al., 2018) which will be a big step forward.

Maybe Asperger syndrome and high-functioning autism will no longer be subsumed to Autism Spectrum Disorder in the future. If so, it would be in line with the conception of a "narrow neurodiversity" proposed by Jaarsma and Welin (2012). Maybe the aspies and high-functional autists will totally escape from the next editions of DSM and ICD, as the autistic activists suggest. Baron-Cohen (2017) posits – but we cannot fully – agree that the neurodiversity alone, if applied to DSM-5, could differently shape hundreds of diagnoses and "revolutionize both the science and the practice of psychiatry". In our opinion, Science (not only psychiatry) can revolutionize the field, rather than ideology. If questions like "what causes autism?", "can autism be prevented?", "can autism be detected in the prenatal stage?", "can autism be cured?" will be fully and positively answered, only then we will understand the power of movement as neurodiversity. Will the parents decide to give birth to a child with autism, if they

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[14] Quote from Janice Joplin English version of Ils ont changé ma chanson, thesong and title of album of Dalida (1970). And I think I'm half insane ma/ Look what they done to my song/I wish I could find a good book to live in/Wish I could find a good book/Well if I could find a real good book/I'd never have to come out and look at/What they done to my song…

precisely know where on the spectrum he will be, in terms of high or low functionality? Will the parents be accused of negligence if they will refuse to allow their child to be treated (medication, neurosurgical interventions)? Will an adult, proud member of the neurodiversity community, take the pill and renounce at his autistic identity?[15]

Maybe I'm right and maybe I'm wrong
Maybe I'm weak and maybe I'm strong…[16]

We raised questions more than provide answers but no matter how those questions will be answered in the future – in terms of diagnostics, interventions, cure or labels – our creed stands firm: every child and every person are unique and deserve to be looked at for their strengths and valued for what they are and not for what they are expected to be. The author's personal position is rooted in Existential analysis and Positive psychology and therefore the plea for not unnecessary pathologize, not over-diagnose or over-treat mental disorders in general and autism in particular. From an existential viewpoint, we argue that autistic people must always be seen as persons first, whatever the diagnosis, the labels, the actual or future political claims will be. Autistic people fully deserve respect, state and societal support without being forced to fit into a (medical or neurodiversity) model. We will close with an invitation to approach autism exercising a phenomenological attitude, addressed to all those involved in the field:

> One needs to reflect on one's own pre-understandings, frameworks, and biases regarding the (psychological, political, and ideological) motivation and the nature of the question, in search for genuine openness in one's conversational relation with the phenomenon.
>
> One needs to overcome one's subjective or private feelings, preferences, inclinations, or expectations that may seduce or tempt one to come to premature, wishful, or one-sided understandings of an experience and that would prevent one from coming to terms with a phenomenon as it is lived through (Finlay, 2011: 83).

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[15] "Autism is a world" documentary: "As a person who lives with autism daily and will not live a normal life, I find peoplewho are high functioning and saying society should not look for a cure offensive. Theyhave no idea what our lives are like. Killing autism lets me enjoy a life with greatfriends and allows me to go to college, but I must never let down my guard or autismwill take over. I don't want any more children to live, as I must, in this constant state of war" (Rubin, 2005 quoted by Ortega, 2006).

[16] Lyrics from Nevertheless song by Frank Sinatra "Maybe I'm right and maybe I'm wrong Maybe I'm weak and maybe I'm strong But nevertheless…".

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The social construction of autism as disability

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Introduction

At the beginning, autism was described as a syndrome. We could argue that autism didn't exist until it was described in term of observable symptoms. The first description of autism prompted us to understand it from the beginning as a medical condition. Over the years, we revisited our understanding of autism based not only on scientific data from researches, but also based on changing attitudes of people that interest with people with autistic spectrum disorders (ASD).

In this chapter it is not our intention to draw a history of autism, but mere to highlight the ever-changing understanding of autism and the multiplicity of discourses that co-exist today in both scientific and layman language.

We will begin by describing the effect of paradigmatic positioning on autism understanding. For this, we will describe the main issues that are relevant to our topic from medical, cultural, and critical paradigm. Then we will compare what are the effects on education and intervention for children with ASD.

Later, we will focus on the societal attitudes toward children with ASD and their families. We will try to outline an ecological approach of education and support for children with ASD.

In the final part of our chapter we will try to argue for a more aware theoretical positioning of practitioners. We will try to make a case for a holistic view of the child with ASD and his/her family.

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1. Paradigmatic positioning and understanding of autism

Paradigms are both a bless and a course in social science. In natural sciences, paradigms are less frequent, and they tend to replace one another. The paradigm shift came when new data cannot be explained by the old theories and the search for new theories succeed in explaining both the old and new data (Kuhn, 1962). In social science this is not a case. Different paradigms tend to coexist and the new add a new type of explanation that cannot be refuted by using the old theories (Denzin & Lincoln, 2017).

In social science we have at least three paradigms, namely positivism/post-positivism, constructivism/interpretative approach, and critical/emancipatory paradigm (Denzin & Lincoln, 2017). The first is routed in classical theory of science and is based on the assumption that the reality is objective and could be understood through direct observation. The second is based on the idea that the social reality is a construct, or an agreement of social actors based on language. The reality is constructed in our mind as we try to make sense from the world, so the main tool for knowledge is the analysis of our language and social construction. The last is based on a historical, dialectical or Marxist approach that stresses the divide in society and promotes a science whose aim is to improve reality rather that to describe it.

In disabilities studies, the above-mentioned paradigms are embedded in several different models of disability.

Autism started off as part of the *medical model of disability*. According to this model, autism is a disease. As we mentioned in the introduction of this chapter, autism birth is the description of its central symptoms. The medical model based on observable symptoms that are combined into a syndrome with various forms follow the path of describing other mental disorders. This is not surprising because from early on, autism was sometimes described as infantile schizophrenia (Al Ghazi, 2018). The medical model of autism has, undoubtedly, it's merit. First, it focuses on early detection and diagnosis. Such a detection is based on objectively behavioural symptoms, that should limit the number of false identifications. The most used tools for assessment and diagnosis are based on two manuals developed by medical institution. The Diagnostical and Statistical Manual of Mental Disorders (DSM V) is developed by the American Psychiatrist Association. The International Classification of Functioning (ICF), derived from International Classification of Diseases (ICD 11) is made by the World Health Organisation and offers a comprehensive description of a medical-social model of deficiency, disability and handicap. In this respect we could say that the medical model is a positivist one, that treat autism as an objective condition that could be identified and treated accordingly. The other benefit of this approach is that it offers a clear path for intervention. The intervention focuses on reducing specific symptomatology and increasing the body and mental functioning. On the other hand, as all diseases and disorders, the locus of autism is at individual level, as there are the resources for treatment. That ignores the functioning in social context and the way the autistic child interacts with the world.

A competing model is the cultural model, originated in United Kingdom. According with this model, all people are mere different version of an idealised model of human being (Barnes, Oliver & Barton, 2008). In other words, we are all different from one another so it impossible to locate the disability at individual level. The disability arose when society defines some traits as "good" or "acceptable" and others as "bad" or "unacceptable". Usually the most frequent traits are considered normal and the other are considered abnormal. Then, society makes rules and arrangements that favours the normal traits. Think about the fact that most of appliances are designed for the right-handed, or that most of the constructed space use visual cues. Of course, that the minority that doesn't possess the necessary trait is in a disadvantaged position. The result is a growing discrepancy between the groups and an increased isolation of those that are different. According to this model, the society is disabling people. Autism falls into the same discourse. People with autism are a form of human diversity and we should take their needs into consideration when we describe normal social functioning. This approach is clearly a constructivist one that promotes the reconsideration of our social values and promotes social change. The source of disability is outside the person, in our societal and cultural values.

Closely related is the American cultural model, that assumes that people with disabilities (autism included) are a cultural minority. As a cultural minority they should have specific rights when it came to self-expression, inclusion or civil rights. This model is an emancipatory one, based on highlighting the social injustice toward people with autism and affirmative actions.

Finally, there is a post positivist model originated in Scandinavian countries. The model defines disabilities as a mismatch between individual resources and environmental resources and demands. In this case we should strive to change both the person and the environment for an improved functioning. The source of disability is in the interaction between person and its environment. According to this model, the intervention should follow the principle of *least restrictive environment* (Davis, 2006) that aims to make minimum required modification in both environment and children to close the gap between the individual resources and environmental demands.

Some key issues are to be addressed when it comes to autistic spectrum disorders, and different specialist, from different perspectives, have different approaches.

Should we try to change the children with disability or the environment?

Depending on the theoretical positioning, some will advocate a children focused intervention with two goals: to develop children's skills and world understanding, and to teach him/her standard behaviours that are appropriate to specific situations.

Others will focus on the authenticity of every diverse population and will require a focus on social condition of children with ASD. In that case, the goal is to build a more inclusive, diverse and tolerant society.

Finally, there is a kind of functionalist approach that suggests holistic intervention, both at individual, relational, and societal level. Such a perspective is also favoured by us.

Our main argument for an ecological approach is that autism is a condition that doesn't affect only the child, but also families, human relations and social policies. For us is clear that we need to make intervention in child's life space.

Should the treatment be based on behaviour modification or on cognitive reframing?

Therapies that are symptom driven are quite popular in the treatment of children with ASD. The approach is not wrong as long as ASD is defined by observable and measurable behavioural symptoms. Some of the psychologists will suggest that this is the only data driven therapy and, subsequently, the only scientific approach. Another important factor is that they are championing a behavioural approach of learning.

Opposite to this theoretical approach is the cognitive one that stresses the cognitive undertone of every behaviour. Also, theories of mind suggest that children with autism have difficulties in interpreting reality. So, at least in theory, intervention based not only on behavioural learning should be more effective. Unfortunately, this line of research does not make yet a significant impact although cognitive behavioural therapy shows effectiveness in some area like treatment of anxiety or training social skills.

Should we change environment, attitudes or both?

Regarding social intervention, again, there are more option. Some suggest that we need a total social change in order to make social environment a truly inclusive one, where there is no discrimination based on disability, gender, race, age, ethnicity or sexual orientation. Other suggest that society has a disabling effect on people with ASD due to unrealistic demands for them. As an example, our education does not favour children that are different to succeed. Attitudinal change, at society level is never an easy or quick task. But, the increased exposure in media shows a positive effect on ASD understanding and acceptance.

Why an ecological approach?

All ecological approaches are based on the idea, that we are social animals that live in symbiosis with our environment.

Society is not merely a sum of people, but an extremely sophisticated network of relations. It is so complex, that we needed to develop a language and cultures in order to regulate and manage all this complexity.

Autism, by definition, is an inability to navigate in such networks due to a lack of understanding it and poor social and communication skills. That put people with ASD in danger of isolation and/or exclusion from the vast social network.

As humans, we live in a limited environment, that should provide resources for our needs. What in interesting, is that this environment isn't only a physical one, but also a social one and a symbolic one. The social environment has multiple ramification, but it starts with parents and siblings, continues with relatives and friends of the family and extends in different ways like parent's workplace or children's school (Goodley, 2011).

The symbolic environments consist in language, communications, values, norms and all intangible aspects of a culture.

Also, our needs are not exclusively physical, but also social. The basic, instinctual need are the base of the hierarchy of needs, but higher we climb on this hierarchy, more social and cultural are these needs.

An ecological model of ASD intervention is a schema of a much more diverse situation, but it highlights the main issues.

First, the child is our main focus. As any other person, the child with ASD lives in a specific environment or ecological niche. The most significant environment is the family. The family provides subsistence, safety, acceptance and social and emotional support. Also, the child with ASD is part of the family system and change it constantly. Since the birth, the children with ASD change the family, its relations, its focus et al. Having a child with ASD in family is a game changer. That is why we believe that the intervention should include family at all level, from goal setting to final assessment.

If we put the children in the centre of our model, from an ecological perspective, we should define his/her life space or ecological niche. Following Bronfenbrenner model (Bronfenbrenner, 1979), we should describe it in terms of microsystem, mesosystem, exosystem and macrosystem. At the more intimate level is the family as the functional unit of support for the child with ASD. All the other significant microsystems, like school environment or other peer interaction groups or other support groups need to mediate their influence through family (Kasari et al., 2011). That is why at the mesosystemic level, any therapeutic intervention, even the assessment needs to partner with family. More than that, we strongly support not only child's assessment and child focus intervention, but also family assessment and family directed intervention and counselling (Predescu, Al Ghazi, Dârjan, 2018).

If we take a functional approach, and we acknowledge that changes have to be done both at child and its environment, than, at least a part of the intervention should also assess the mesosystems, more specifically possible opportunities and threats in related environment such as medical care system, parents' occupational status, and available services.

Not least important, at the macrosystem level lies the values and our core believes about children with ASD. The most challenging and time resistant task is to negotiate a new social understanding of children with ASD, focused more on the positives than negatives. The social change does not occur easily and almost always, the final result is different than predicted. That doesn't mean an impossibility of meaningful social change. The last decades were a great step in changing autism social acceptance (Dârjan & Luștrea, 2018).

Is the theory just an intellectual game?

From an epistemological and methodological perspective, we should ask ourselves if the theoretical debates add or reduce the uncertainty in the practice of helping children with autism.

Once we established that ASD is a real condition (either medical or social constructed one), the issue is if we could define a best way of understanding based of specific methods.

The paradox is that the competing theories in the field gives us a map of understanding autism, and so, it helps us to better advance our intervention. But how it is that possible?

Think of theory as a different map of a physical space. If it is a Mercator map projection or an azimuthal one, like lambert, or conic projection, they all represent the same space. And all of the are just an approximation of physical space and have distortions. But all of them helps us to navigate from point A to point B. The real value of the map is in its utility for the purpose, and its availability.

When it comes to theory, the value of it resides in its utility for planning interventions. But what is different from our map example, autism is not such a clearly defined space. So, we must take account on the fact that our choices are not only technical, but also are baking different moral position. And this is precisely why we think that practitioners should have a better theoretical grounding and understanding.

The medical model is focused on a cold, technical approach of ASD. The model promotes a limited social understanding of ASD and its effects on families and school. The intervention is usually based at individual level.

The social model of ASD leads to inclusive measures, especially in school functioning, but tend to underestimate symptoms reducing interventions. The interventions are most common centered on developing support networks for children with ASD.

The critical model is the most acknowledgeable of the social conflicts that are accompanying ASD intervention and is the most focused on reducing social tensions. This model is the most global but tend to be forget that the child with ASD should also try to adapt to different existing social environments.

As a conclusion, we think that theoretical positioning is a necessity if we should be fully aware about our interventions. As practitioners we are able to have theoretical flexibility and to adapt our actions accordingly. If we want to make an advocacy action, to promote child's right to a meaningful education, I will position myself on critical grounds. If I want to develop a clear support network at school level, I will emphasize the need of school change from a social perspective. But if I want to develop a specific skill of a child with ASD, probably the intervention will be from a scientific established therapy, such as ABA or Son-Rise or TEACCH.

Autism, like most of mental condition, is a social construction. The meaning of ASD and the way we respond to its changing nature is also a social scientific construction (Evans, 2012). Contextualizing intervention is the best opportunity to make change not only at individual level, but also at an ecological niche level. Wholistic intervention that treat not only symptoms, but whole families, are our best options.

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Second part

Aspects of Development, Intervention Methodologies, Researches on Autism

Case management
in Autism Spectrum Disorders

Anca Luștrea[1]

1. Case management - a framework for effective interventions

In nowadays an abundance of new methods and techniques in addressing autism spectrum disorders (ASD) make it difficult to select and implement the best intervention schema. The heterogeneity of spectrum's symptoms and different levels of functionality determine a singularity of manifestations and developmental trajectories. Every child is unique and cannot be put in a fix diagnostic pattern or intervention prescription. We ask ourselves the question about how can we design and implement an effective intervention plan for each child, if there is no established pattern and the behaviors differ so much?

The most important answer to that question is to approach each case in an individual manner (McDonnell, McLaughlin & Morison, 1997). After all, we as specialists and even more the family, don't aim to fit the child into some patterns but to find the right formula to adapt and lead a functional life. We must seek the best combination of techniques, methods, curricular adaptations and accommodations that positively impact each child and helps him integrate and live a full live.

The second answer to the question is inter-professional collaboration (Summers et al., 2016). Only in a mutual effort made by the specialists, family, community and the child we can find our path in this complex endeavor. Each of those above can contribute in a specific manner to the intervention, but only by a joint perspective and effort can make it effective. The family put the child's interest above all and know him best, the specialists manage all the activities and intervene, the community creates the social framework for inclusion,

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accessibility and participation and the child puts a great time and effort to adapt and progress.

The case management is the proper framework to satisfy both principles of individual approach and collaboration. Case management can be defined as a methodology (Garcés & Ródenas, 2015) through which all the interventions and action of professionals from medical, educational, therapeutic and social fields are coordinated and organized in a scientific manner. It is also defined as a "rigorous working method, which aims at coordinating and monitoring all activities carried out in the interests of intervention and the support of child and his, family in order to develop and fully exploit the potential and resources available to them" (Gherguţ, 2011: 176). Through case management the focus is put on the child's ecological development, relative to his environment and significant relations. The strengths as a starting point, the child's needs, developmental milestones to be reached and targeted behavior modifications are taken into consideration from different perspectives but unified in a common view. The child's with ASD needs are so diverse that a single specialist cannot satisfy them all. A multidisciplinary team is selected and designated to work with the child. If each team member works independently the progress is not significant. But if they combine their efforts in a joint perspective the child's progress can be optimal.

DSM V (American Psychiatric Association, 2013) introduced a new perspective on ASD, of a continuous spectrum of manifestations and different grades of functionality. The focus is put on qualitative description of adaptive behaviors and the level of autonomous environmental mastery.

The ASD case management should comply to this new perspective and assess the effectiveness of intervention by the same criteria: the child's progress in terms of independent living skills and needed level of support. To be effective, a psycho-pedagogical intervention needs structure, a scientific approach, a complex view of the child's needs from an ecological perspective and consistency.

An effective case management needs *structure and a systematic approach* to intervention (Ross, Curry & Goodwin, 2011). Only a very good designed plan, with aims, operationalized long and short terms objectives, intertwined activities which follow the steps of developmental trajectory and rigorous feed-back monitoring sessions can assure the basic foundation of a successful intervention.

All the intervention processes, from the initial evaluation to monitoring, needs to be tackled in a *scientific manner*. Each member of the multidisciplinary team comes with a specific scientific methodology and contribute to the intervention's advance. But not just the therapeutic and educational activities should be carried out in a scientific manner. The case management process itself should be treated as a scientific domain and the proper methodology applied.

The complex nature of the case management resides from the child's complexity of needs. ASD impact the child's development from multiple perspectives: social communication and interaction, atypical patterns of behavior and interests, school adaptability or learning pace. Each child has its own rhythm of development, with ups and downs, with progress, stagnation and even regress at some point. Sometimes, the factors that determine the developmental curve cannot be determined and an absolute correlation between developmental phases and factors that occur cannot be drawn. Therefore, it is important to have an *ecological perspective* of the child. In any moment we should be able to link the child's behavior with the context and the social interactions. To do so we should know and understand the child in all his significant environments and relations.

Consistency and perseverance can ensure the systematic nature of the intervention (Ruble, Dalrymple & McGrew, 2012). Despite the low points and even regress the intervention should continue, finding new ways, better adapted. It is normal that with the child's growth his ways of interaction and his needs to change too. If we remain rigid in the same intervention schema it can become overdone for that stage of development and the child stagnates. So we should conduct an *adaptable and flexible* case management centered on the current needs of the child.

2. Domains of intervention in ASD

The general principles and processes of case management apply to ASD also, with a certain specificity given by the spectrum specific characteristics. First principle refers to the multidisciplinary team component, which must reflect the main domains of intervention. In ASD the cardinal domains of intervention are social communication and interaction, language and communication, behavioral change, sensory integration, adaptive living and academic learning. For each area a specialist should be co-opted in the team to contribute with his expertise to the team effort. In Figure 1 the main area of intervention and their interconnectivity are presented.

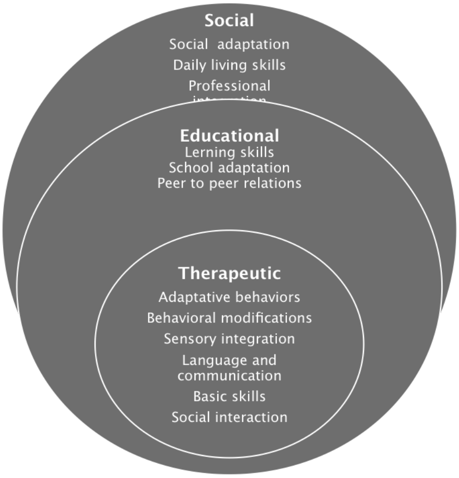

Figure 1. Domains of intervention in ASD

In early intervention the focus is put on the therapeutic domain. In the beginning the priorities lay on developing a therapeutic relation as a base for all progress. Social interaction, from establishing eye contact, joint attention habits to reciprocity in actions stand at the foundation of learning. Also, basic skills should be acquired, such as focus on task, be attentive, cooperate or show flexible interests and patterns of action. Language and communication can be viewed as basic processes also. Without the capacity of communication and social interaction the mediated learning cannot occur. Sensory processing difficulties are frequent in children with ASD, Baranek (2002) estimates a prevalence between 42% and 88%. These difficulties can lead to self-stimulating behaviors which are destined to compensate for low sensory input or avoid overstimulation (Schaaf & Nightlinger, 2007). Addressing the sensory processing difficulties can resolve a great deal of the child's environmental adjusting problems. Behavioral modifications are necessary from the beginning to replace the non-functional patterns of behaviors with adaptive ones. The adaptive skills are considered to be one of the best predictors of functioning and independent living (Hill, Gray, Kamps & Enrique Varela, 2015). In the early stages the children should learn adaptive patterns to dress, feed, toilet use, fell asleep or play.

Through the therapeutic intervention the development of basic social and functional skills by the school age is targeted. The school inclusion from the beginning is an aim that should be addressed if a least restrictive environment is intended to be provided. The educational intervention is complementary and continues the therapeutic effort. They intersect and complement each other, have common goals and address the same needs, but with different methodologies. The school provides opportunities to deliver an comprehensive intervention aiming attention at improving communication and socialization, and enlarging the child's with ASD interests (Koegel, L. et al., 2011). The school environment is propitious for developing peer to peer relations. The child is emerged in a social climate that offers him typical behavioral models, chances of interaction, social learning situations and standards of social rules. To progress and be included the child should develop adaptation skills that lead to personal progress. Also, the school is the best environment for learning, where the child can master knowledge and learning skills and develop positive attitudes toward self and others. But to be truly a useful process, curricular adaptations and differentiated instruction should be carried out (Strogilos, Avramidis, Voulagka & Tragoulia, 2018).

The social domain is permanently aimed in all intervention's stages. The difficulties in social communication and interactions are a defining feature of ASD and an essential need that should be addressed from the beginning. Objectives from the social domain should be found in both therapeutic and educational activities. In early intervention basic social skills are targeted, such as: establishing eye contact, development of non-verbal social gestures such as showing, pointing, waving and giving, or promote joint visual attention (Freye, 2018). Later on the focus is put on learning through peer mediation of skills, to develop appropriate requesting, commenting, and sharing (Morrison, Kamps, Garcia & Parker, 2001). At preschool age the targeted skills include play skills (e.g., reciprocal interaction, turn-taking, pretend play, following rules, sharing, etc), social communication skills (e.g., question, starting and responding in conversations, understanding non-verbal communication), friendship skills and socio-emotional skills (e.g., empathy or affect recognition) (Gillis & Butler, 2007). At school age the prevalent difficulties include starting and maintaining interactions, perseveration on activities, turn-taking, perspective-taking and identifying and interpreting emotions (Koegel, L. et al., 2011). In the transition from school to adulthood crucial areas to be addressed are education, community living, employment and community integration (Hendricks & Wehman, 2009).

All three domains are interrelated and support each other. In the case management process developmental objectives are formulated from all the areas of intervention and prioritized related to the most stringent need of the child.

The case management process includes pre-referral, referral, evaluation, establish eligibility, development and implementation of the IEP and monitoring. All these stages are designed to reach the optimal level of functionality and social inclusion. Being a complex process requires a multidisciplinary team to be carried out. Specialists from various domains and the family collaborate to reach the maximum potential of the child. To address every need, the multidisciplinary team should be composed from psychologists, psycho-pedagogues, speech therapists, auditory and visual therapists, physical therapist, teachers and special educators. Nancarrow et al. (2013) enumerate 10 principles of a good interdisciplinary team: good communication, respecting/understanding roles, appropriate skill mix, quality and outcomes of care, appropriate team processes and resources, clear vision, flexibility, management, team culture – companionship, team support, and training and development opportunities. A good team can be consolidated over time, so it is necessary to keep a consistent and continuous team structure. The school can provide such a consisted environment, beneficial for organizing and maintaining team work.

3. Multidisciplinary, interdisciplinary or transdisciplimary case management?

The most common case management model is the multidisciplinary one. But is still valid and can satisfy the complex needs of a child with ASD? In table 1 are presented the main characteristics of the three models of case management.

Table 1. Models of case management

Multidisciplinary CM	**Interdisciplinary CM**	**Transdisciplinary CM**
Individual responsibility	Team responsibility	Team responsibility
Complementary activities	Complementary activities	Transdisciplinary activities
Multidisciplinary activities	Coordinated, integrated services	Coordinated, transdisciplinary services
Independent assessment	Independent assessment	Transdisciplinary assessment in arena
Independent intervention planning	Collaborative intervention planning	Collaborative intervention planning
Independent intervention	Independent intervention	Role sharing beyond specializations
Independent monitoring	Collaborative monitoring and reflection on the process	Transdisciplinary monitoring and collaborative reflection

All three models of case management are child-centered and put the child's needs in the center of the process. The main difference between them is the level of collaboration between specialists. The most collaborative model is the transdisciplinary one, in which collaboration reach the level of role sharing between specializations. In the transdisciplinary model all intervention processes are carried out in a transdisciplinary manner: the arena assessment, coordinated planning, role release in activities' implementation and sharing expertise (King et al., 2009). The least collaborative model is the multidisciplinary one, in which all activities are carried out independently. The team offers services in all necessary domains, but the level of collaboration is minimal. The team members assess the child separately, plan and implement activities independently. However, they meet regularly, share information and coordinate activities for similar objectives. An intermediary model between those two is the interdisciplinary one. The level of collaboration is high but does not reach the role release from the trandisciplinary model. The assessment and activities is still performed independently by each team member, but the intervention planning, objectives' prioritization and monitoring/reflection on the intervention process are accomplished collaboratively.

Most certainly, the higher the degree of collaboration between the team members, the greater the child's benefit is. The progress is conjugated in a few important areas in small time intervals, all the specialists aiming the same final result. If the collaboration is minimal the effort is dissipated in more directions and the child doesn't progress so fast and with no sustainable acquisitions. From this perspective, the transdisciplinary model seems to be the best, but the necessary level of expertise is high and the resources multitudinous.

Table 2. A SWOT analysis for the three models of case management

Strengths			**Weaknesses**		
Multi-disciplinary	Inter-disciplinary	Trans-disciplinary	Multi-disciplinary	Inter-disciplinary	Trans-disciplinary
Most known Evidence based Fewer resources needed	High level of collaboration Best for school setting Interdisciplinary perspective	Excellent level of collaboration High expertise Applied in natural setting	Low level of collaboration Dissipated effort Slow child progress	Needs collaboration expertise Needs high supportive conditions Needs collective creativity	Implies high resources Needs a special expertise High costs

Opportunities			**Threats**		
Multi-disciplinary	Inter-disciplinary	Trans-disciplinary	Multi-disciplinary	Inter-disciplinary	Trans-disciplinary
Can be easily applied Team members can be from different institutions Starting point for collaboration	Very good child progress Determine sustainable acquisitions Collaborative learning	Close collaboration with family Learning in natural setting Transform daily activities in learning opportunities	Routine setting Family refuses collaboration Formal process, without positive consequences	Lack of space and time for meetings Specialists do not know how to collaborate Specialists do not want to collaborate	Lack of resources Lack of funds for home-intervention Lack of specialist

Each model has its own benefits and setbacks (Table 2). Each model should be adopted depending of the intervention stage and the developmental needs.

In the early stages of intervention, the transdisciplinary model is recommended. It can be carried out in the home environment, the behavioral observations completed in the child's natural environment, new behaviors and skills can be learned in the daily living climate. The family can be taught to observe the child's behavior and perform therapeutic activities. For young children with ASD it is difficult to relate with many different adults, so the trandisciplinary model, in which only a few specialists directly interact with the child, is best suited. For the school age the interdisciplinary model is convenient. The school offers the best environment for organization and implementation of an interdisciplinary team. In school all kinds of specialists can be found, from psychologists to special education teachers. The school provides the opportunity to meet and collaborate on daily basis and coordinate the process through curriculum planning. For the last stages of intervention, transition to adulthood and follow-up, the coordination requirement is not so decisive, and the specialist could be from different institutions, so the multidisciplinary model should be applied.

4. Case management in early intervention in ASD

Early intervention is an essential condition for achieving success. Only if the therapeutic process is started as soon as possible after the diagnostic we can say that the intervention is on a good path. the long term aims for early intervention are: optimum development and social integration of children with ASD, reducing the social costs involved in special education and later in social assistance and supporting the families to meet their children's needs. Between the most important benefits of early intervention are:

- substantial progress achieved in all areas of development;
- preventing secondary (comorbid) disabilities;
- reducing family stress;
- reducing the dependence and special institutionalization;
- the need for special education measures is reduced;
- reduce of social costs.

To be effective early intervention services need to:

- be offered in the least restrictive environment and as natural as possible (Brown, Benson McMullen & File, 2010;
- be family-centered and meet its needs;
- be guided by the empirical results obtained in working with the child and his family;
- be individualized and adapted to child's age and needs.

In ASD early intervention case management should be transdisciplinary. The transdisciplinary model provides coordinated, integrated, interventions to fulfill the needs of children with disabilities. Transdisciplinary team is defined by the involvement of all members in learning, teaching and working together to put into action integrated services (Fewell, 1983, apud. King et al. 2009).

The transdisciplinary approach is characterized by the transfer of roles between team members. All the roles in the therapeutic and educational domains are conducted in a joint manner. All members engage in each activity, sharing knowledge, findings, methods, and experiences. Each team member participates in the decision-making process, the boundaries between specializations are removed.

York et al. (1990: 73) state two specific elements of the transdisciplinary teams:

> - A high degree of collaboration and joint decision-making among team members (including parents) in conducting assessments, establishing program priorities and designing and implementing individualized educational programs;
> - Teaching the skills traditionally associated to one discipline to other team members who function in direct service capacities and work directly with learners throughout each day across a variety of environments and activities (role release).

King et al. (2009) listed three main characteristics of the transdisciplinary model:

- The arena assessment: Each child is assessed together by all team members, adopting both standardized and informal methods. One specialist has the facilitator role, while others relate with the child and others observe and take notes. After assessment a meeting is conducted to change information and interpretations.
- In-depth interaction between team members through the whole intervention to share information, make decisions together and work collaboratively.
- Role release: "The team becomes truly transdisciplinary in practice when members give up or "release" intervention strategies from their disciplines, under the supervision and support of team members whose disciplines are accountable for those practices. The role release process therefore involves sharing of expertise; valuing the perspectives, knowledge, and skills of those from other disciplines; and trust-being able to "let go" of one's specific role when appropriate" (King et al., 2009: 213).

The transdisciplinary model is the best fit for early intervention services for children in the spectrum. For them it is difficult to establish relation with a great number of people, that's why it's important to deliver services with minimum number of specialists. However, the children's needs transcend one domain of intervention. The transdisciplinary approach provides services in all domains but conducted by a small number of specialists, through role release and sharing information. For the children on the spectrum the home environment is the safest and comforting space for learning. Delivering services at home help them to be emotionally reassured but also to learn new skills directly in the daily living environment. It is the easiest learning modality because it is no longer necessary for the new acquired skills to be later transferred.

5. Case management in schools

Reaching the school age can be a difficult period for both the child and the parents. New challenges and requirements stands in front of the child's development and the focus is put on social integration in the school environment and in learning. Depending on the level of functionality reached by this stage, the specialists together with the family must decide of the best educational placement option: mainstream inclusion or special education. For mainstream inclusion the social and learning demands are more extensive and difficult to meet so the child should master a necessary level of verbal communication and social skills. But the child also has needs that cannot be meet in the services provided by school and can participate to out-of-school services (such as medical, nutritional, cultural). Therefore, an integrated case management model is the best option for this stage (XXX, 2000).

An integrated case management approach provides the opportunity for collaborative service delivery, an interdisciplinary joint effort in managing the child's in the spectrum complex needs. The model offers direct supervision opportunities, the majority of case management control and guidance is provided face to face by a certified specialist. In the integrated approach the services delivered prior to entering school can be integrated and a continuity of support assured.

In the school context the needs of children's in the spectrum can include: curriculum planning, curricular adaptations, social interaction support, social communication development, designing accessibility, and support for adaptation to the school demands. Beside them any child from the spectrum can have additional needs, such as health needs (nutrition, life-style, medical), family needs (relation with parents, siblings or extended family), behavioral and emotional needs, and self-care needs. These can be addressed by specialists outside of school but should be integrated in the whole Individualized Educational Plan (IEP) and services coordinated by the case manager at school level.

Some of the children may prior have followed with success specific therapeutic programs, such as ABA and need to continue it further. ABA can be applied in the school setting with success, but specialists certified in ABA must be provided by the school. ABA principles can be applied to learning, new academic skills should be teach to become instrumental for the child and capable to address complex problems (Martens, Daly & Ardoin, 2015).

6. Case management in transition periods

Children in the spectrum may feel distress and anxiety to the unknown or new situations. For them the transition periods are more difficult than for others and in the process of case management we should plan in advance to be prepared for them. Transition periods include the shift from one activity to another, from one setting to another, progression through grades and the transition to adult life.

The goal in planning the transitions is to develop coping skills that best help the child to adapt and find resources to overcome obstacles and maintain an emotional balance. These skills may include emotion recognition, emotion management, help seeking, plan for structured daily activities, keep time and track changes. Periods for adjustment are necessary the child should be progressively introduced in the new environment and routines. For example in kindergarten to school transition a period of six month progressive adjustment is needed. The child should be presented with the new learning environment, the future teachers and if possible colleagues, taking preferred classes one or two times per week in school, participate to extracurricular activities. At the beginning extra support is needed to facilitate transition, in different degrees for each child, for some even a support teacher is necessary. Parents play an important role in transitions because they should play the facilitator role between teachers and child. They should meet in advance the case management team, discuss the child's needs, progress and routines and establish a bond.

The transition from school to adult life should be planned with much time in advance because it implies career decision, residential options, post-secondary education, and employment possibilities. This decision should be a result of a collaboration process between all case management team members, including parents and if possible the child. The follow-up process conducted by the case management school team can put the early foundation for the case management over the life span. In adult life the person in the spectrum may collaborate and be supported by various residential and community institutions, different providers of specific services and that make the case management process more difficult. A multidisciplinary model is the easiest to adopt, but still collaboration must be an important feature.

Conclusions

Children in the spectrum present various and complex needs that can be meet only by a scientific and rigorous methodology, the case management framework. There are several models for case management: multidisciplinary, interdisciplinary and transdisciplinary. Each has strengths and weaknesses, and is appropriate for certain levels of development, functionality or type of skills that need to be mastered. For early intervention the transdisciplinary approach is best suited because provides the opportunity of learning in the natural environment and interact with fewer specialists. In school the interdisciplinary model can be applied the easiest. The school provides specialists in different intervention fields but also specialists trained to work in the case management structure, and the suited environment for meetings and sharing knowledge. In planning for transition to adult life a multidisciplinary approach can be necessary because of the diversity of providers and social domains that will be access by the person in the spectrum (professional, residential, cultural, community). If the level of autonomy and functionality by the end of school is not optimum case management services for the life span should be provided through community support services.

Through case management a high degree of autonomy, functionality and social integration is aimed. Qualitative and individualized services should be planned throughout developmental stages for achieving these goals. Planning for intervention should be an adaptable and flexible process that takes into consideration personal and developmental specificity but also progress, stagnation or even regression phases. Perfect understandings of the child is the nodal point in developing appropriate services and obtain success.

There is no standard intervention schema for children in the spectrum. The intervention planning is an evidence based and response to intervention process, when over the results we select the most successful methods, techniques and accommodation for each case. The case management team, including the parents should demonstrate patience, perseverance, trust and more important unconditional love to make the intervention not only efficient but also emotional significant for the child.

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Assessing Children with Autism Spectrum Disorder

Daniel Mara[1], *Elena Lucia Mara*[1]

1. Assessment of Autism Spectrum Disorder

The Autism Spectrum Disorder (ASD) is one of the most common developmental disability after the intellectual disabilities and cerebral palsy. The number of children affected by ASD is higher than those with diabetes, cancer or AIDS altogether. TSA affects between 2 and 6/1,000 people. ASD is more common in boys than girls.

According to a recent Cambridge University study, 1 in 58 children is affected by TSA in the UK. Autism is not conditioned by geolocation, race, ethnicity or social class or cultural level of the family. In Romania, by 2012, there were 7,179 people diagnosed with autism (according to the Ministry of Health), but their actual number is much higher, most of them not being officially registered. There is no statistics on the number of people with autism (children, young people, adults). It is estimated, according to international prevalence (NIMH, USA), that there are over 30000 children affected by ASD.

According to the criteria outlined in the the *Diagnostic and Statistical Manual* prepared by the American Psychiatric Association (last revised in 2000 and known as DSM-IV-TR™) and the the *International Classification of Diseases*, prepared by the World Health Organization (currently in its tenth edition and known as ICD-10), to be diagnosed with autism, a child shold have atypical behaviors in social interaction or language as used in social communication, or symbolic/imaginative play at the age of 3 years. One child could not have all of the meaning criteria for autism, he or she may be appropiate with diagnosis of Asperger syndrome (AS) or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Moreover, lately the concept of an autistic syndrome has been developed in order to permit a spectrum – a

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number of disorders reflecting some different patterns of symptoms, and collectively known as autism spectrum disorders. (www.birminghambeheard.org.uk).

The evaluation of the children is a complex process through which the collection of the essential information is pursued in creating a real profile that allows the transition to the next stage, that of designing the future intervention actions. Not being, by yet, a biological analysis for ASD, a diagnosis of ASD is done considering only behavioral profile, as the absence or a presence of atypical behaviors.

The terms *autism* and *autism spectrum disorders* (ASDs for short) it may occur during this chapter, as a definition of this spectrum, about the meaning of the autistic syndrome, this will be referred to as classic autism; the terminology relevant to other sub-types of ASD will be introduced as necessary.

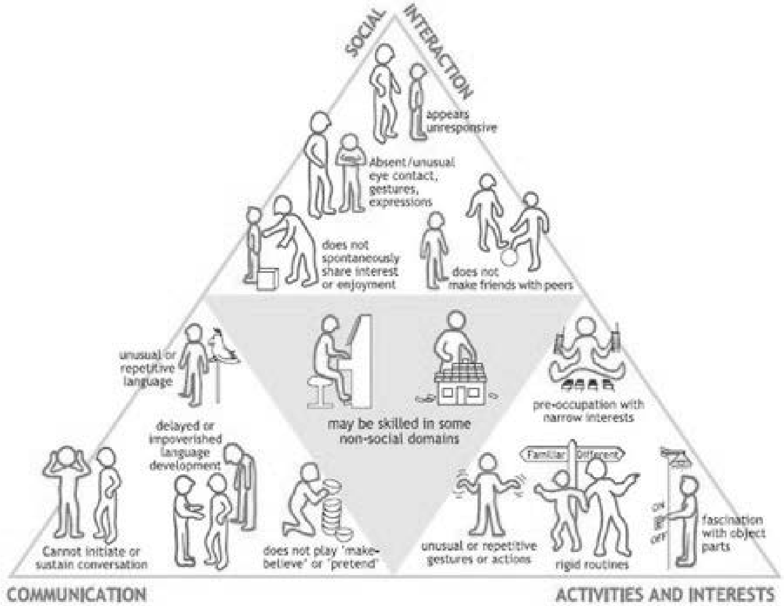
This so-called triad consists of impairments in:

- reciprocal social interaction;
- reciprocal communication;
- scope and range of activities and interests.

It is a fact that males are more likely to be affected by ASDs than females: one quorter for for classic autism and one tenth for ‘milder’ conditions within the spectrum.

The diagnostic criteria currently used are primarily the result of Creak (1961), Rutter (1978) and Wing (1979, 1993). All Diagnostic Systems (ICD 10 - International Disease Classification developed by the World Health Organization and DSM IV-TR - Manual of Diagnosis and Statistics of Mental Disorders, 4th edition, revised text, 2000, developed by the American Psychiatric Association include the Pervasive Developmental Disorders category, which includes 5 diagnoses: Autistic Disorder, Asperger Syndrome, Rett Syndrome, Disintegrative Childhood Disorder, and Pervasive Developmental Disorder - Non-Specific / PDD-NOS. All are characterized by impairment of communication capacity and social interactions, as well as repetitive and stereotyped behaviours. These qualitative interferences characterize the affected person deeply, manifesting to varying degrees in all life situations. They may appear from the youngest child until the age of five, and never resign. By specialized intervention it can be significantly improved. Sometimes, people with autism are classified as “low-functioning” and “high-functioning”, the latter having no associated mental retardation. There are many similarities between people with autism with good functionality and Asperger syndrome.

"Autistic spectrum" (also called "autistic continuum") refers to the conception that autistic disorders would not differ qualitatively, but only quantitatively (the degree of severity of the disorder) that includes "autistic features", the broader autistic phenotype. Pervasive developmental disorders are characterized by severe and pervasive deterioration in various areas of development: mutual social interaction skills, communication skills or the presence of behaviour, interests and stereotypical activities. The qualitative damages that define these conditions are clearly deviant in relation to the level of development or mental age of the individual. Childhood autism is by far the most common pervasive developmental disorder. It implies a marked alteration and persistence over time of social interaction, communication, behaviour and restrictive or stereotyped interests. These symptoms must be present before the age of three. Approximately 70% of affected children have different degrees of mental retardation, this being the most common comorbidity cause.



National Autistic Society

Figure 1. The triad of impairments in ASDs (http://www.open.edu/openlearn/health-sports-psychology/psychology/the-autistic-spectrum-theory-practice/content-section-0)

Autism spectrum disorders are recommended to be diagnosed by multidisciplinary teams (psychiatrist, clinician psychiatrist, paediatrician, speech therapist, psycho-pedagogue / special education teacher, social assistant) using validated diagnostic tools: questionnaires, interviews, observation scales. The evaluation involves assessing the individual's behaviour and cognition in the three areas of interest. Regarding *social interaction*, the clinician needs to evaluate the use of non-verbal behaviour in interaction with others. There may be deficiencies in the use of visual contact, facial expression, gestures or other non-verbal behaviours in interaction with other people. A lack of development of human relationships is often present and may result from total disinterest in socialization or from the lack of the necessary socialization skills. Many people with autism do not share their enthusiasm, interests or accomplishments with others.

In contrast to typically developing children, children diagnosed with ASD, and some children even prior to receiving such diagnoses, experience difficulties in achieving milestones and displaying behaviors easily achieved by their typically developing peers. A major area of these difficulties is social: The social behavior of children, adolescents, and adults with ASD differs qualitatively from that of their typically developing agemates. Indeed, impairments in social behavior constitute one of the three general areas of impairments required for an ASD diagnosis:

- retrospective investigations, such as retrospective parental interviews or the investigation of home movies videotaped during the first year of life (or soon after) of children who later receive an ASD diagnosis;
- studies of infants who are at risk for ASD.

The second largest area evaluated by the clinician is *communication*. Typically, there is a delay or a lack of language development. I can lead others to the desired things, but usually do not compensate for the lack of language, through alternative forms of communication, such as the use of gestures. Some people have the echolalia (immediate or delayed imitation of heard phrases or repetition of words or phrases that do not have a communicative function, Allen, 1988). Some acquire a significant amount of words, but lack the necessary skills to initiate or sustain a social conversation. Typically, there is a lack of spontaneity in the game or an imitative game deficit, and when the skills of the game are present, it tends to be solitary, repetitive.

The third area is represented by the *behavioural patterns, interests* *and activities of the person with autism*. They usually have a repertoire of relatively limited interests and activities, characterized by repetitive behaviours and routine attachment. Some show a concern for one or more repetitive behaviours such as aligning objects, collecting unnecessary objects, or having an unusual interest in certain objects, such as trains or elevators. The child can become very angry if there is a sudden change in daily activity, if he is staying in other banks at school or if a piece of furniture is moved. People with autism have repetitive movements of the body, commonly called "stereotypes" or "self-stimulation" behaviours. These include, but are not limited to, finger and hand movements, body postures, creeping, shaking and other manners. These people may experience abnormal attachments to different objects (e.g. a wooden spoon) and / or concerns about objects or parts of objects (clown fascination).

2. Evaluation tools

A mandatory recommendation in assessing the communicative abilities of children with ASD is the selection of investigation tools, which contributes to the outline of a specific profile. On the other hand, the persons involved in the evaluation of children with ASD must take into account the typology of the approach, such as the traditional ones of assessment, which are oriented in particular on the form and structure of the language, while the modern ones of assessment can determine the stage of development of communication skills.

Autism spectrum disorders is characterized by patterns of atypical behaviours and development and that is why it is very complex process of assesment. In the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR; American Psychiatric Association, 2000) we found a decription of symptom profile, related criteria through observation, checklists and standardized tests. A comprehensive assessment is more than an application of a diagnostic criteria, it has to provide an overview of child's history (life, socialization, enviroment), also combined to assets, liabilities and needs. A comprehensive assessment for ASD thus typically evaluates a child's total functioning-intellectual, neuropsychological, communicative, behavioral, and emotional problems. The evaluation of the children is a complex process through which the collection of the essential information is pursued in creating a real profile that allows the transition to the next stage, that of designing the future intervention actions.

The Autism Diagnostic Interview (ADI) can determine the presence of autism in children above the age of 2. It is a standardized, semi-structured interview for carers and adults with autism. The whole interview takes about 90 minutes. It consists of a diagnostic algorithm outlining the DSM-IV or ICD-10 criteria and provides a structure for questions and the interpretation of responses. The instrument focuses on behavior in three main areas: qualities of reciprocal social interaction; communication and language; and restricted and repetitive, stereotyped interests and behaviors. The ADI-R is appropriate for children and adults with mental ages from about 18 months and above. The interview is focussed on 93 items and want to stressed on behaviors in three points: social interaction; area of communication and language and behavior.

The stage of psycho-pedagogical evaluation of people with autism spectrum disorders represents an important stage for the intervention program to be designed and implemented by specialists. As in all such initiatives, the collaboration between the specialists involved in the interdisciplinary team is essential.

The Autism Diagnostic Observation Scales (ADOS) is a tool who permitt analysing communication, social interaction, or imaginative play in children and adolescents. The time of an exam is about 20 minutes. It made "targeted" social situations where the likelihood of a certain behaviour is high. Activities are structured as materials, interactions are less structured. There are 4 tests, depending on the level of development and the child's linguistic expression. Expressive verbal skills should be at least 3 years old for a clinician prepared in this tool to be able to assess the child's social behaviour and functionality. The child assesed needs to ask for help, to demonstrate how to do something, to tell a story, to play with toys or to have a conversation. The Autism Diagnosis Observation Program (ADOS) is an evaluation mode that targets socialization, communication and play and it is dedicated to children suspected of autism or other disorders in the same spectrum. The program contains four parts, each is adapted to different levels of communication and language development, including verbal and non -verbal language. ADOS allows the observer to detect the existence or non-existence of behaviors that can lead to the identification of certain developmental disorders, focusing on the specific expressiveness of the language. As an efficiency, ADOS is conducted over a period of 30-45 minutes in which the observer creates different contexts that can ensure the determination of a certain type of behavior (Murray, 1938) (https://research.agre.org/program/aboutados.cfm).

ADOS is published by Western Psychological Services (WPS) in 2000 and now available in 15 different languages. Experiences proof that it is one of the most important diagnostic tools used in both area, education and health care screening for developmental disabilities. The latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) focuses on the criteria that can be used by any specialist in diagnosing, meaning direct observation in some situations, in order not to be different opinions. Here's what you need to know about the process. ADOS consists of four different modules. (www.juniorleagueofgreensboro.org).

Tests are created to have application at any age:

- Test 1 - using only nonverbal situations for those who do not have communication skills.
- Test 2 - using minimal verbal communication skills, in known situations.
- Test 3 - using verbally fluent and capable of playing with known toys.
- Test 4 - using verbally fluent and capable of playing any with toys.

ADOS is constantly being refined and studied to make it more accurate and useful. The test is on its second major revision and further studies are ongoing. (https://www.appliedbehavioranalysisedu.org/how-is-ados-autism-diagnostic-observation-schedule-used-to-identify-asd/).

If a screener indicates that a child may have autism spectrum disorder, the child should receive a comprehensive evaluation from someone trained in diagnosing autism. This evaluation will often begin with a diagnostic instrument such as the Autism Diagnostic Observation Schedule, or the ADOS-2. The ADOS is a test with different modules to accommodate a range of children. There is a version for toddlers that is play-based. For kids older than thirty months, there are modules that include more conversation, according to the child's language level. This isn't the kind of test where there are right answers. The purpose of the ADOS is to evaluate the social skills and repetitive behaviors the child displays during the test. This means the evaluator is paying attention to things like if the child asks for help when he needs it, gives other people a chance to speak, and follows along with changes of subject. The Communication and Symbolic Behavior Scales (CSBS) is another good diagnostic instrument for toddlers and young children. This play-based instrument is also backed by research, but is used less than the ADOS, which covers a broader age range.

Dr. Epstein notes that even with these tools it is important to be working with a mental health professional who has experience diagnosing people on the autism spectrum. “You want to be working with someone who understands the subtleties,” she says. “For example, a person who has real expertise will be able to distinguish if a child has poor eye contact because the child is shy, versus if there is poor eye contact in the way we expect to see it in an autism spectrum disorder.” A recent study underscores the difficulty in distinguishing between autism and other disorders, like ADHD, using even gold-standard tools like ADOS. Looking at school age kids with high verbal functioning, the study found that found that 21% of children with ADHD-but not autism-met diagnostic criteria for autism when given the ADOS. “The minute that we diagnose blindly based on score, we’re going to misplace a lot of kids into categories”, lead researcher Somer Bishop, assistant professor of psychiatry at the University of California, San Francisco, tells *Spectrum*, an online journal on autism research. “These instruments were designed to assist in clinical decision-making, but they are not a replacement for a clinical brain.” Adds Catherine Lord, director of the Center for Autism and the Developing Brain at New York-Presbyterian Hospital, who developed the ADOS, it’s important to consider the motivation for the behavior. A child with ADHD might avoid an adult’s gaze because he thinks he has done something wrong, she tells *Spectrum*, rather than because of a social deficit. Or, a child’s face might be unexpressive because she is bored or distracted, not because she is less expressive in general.

Screeners and diagnostic tools are ways of gathering information, but they have to be considered in the context of other information from a range of adults who know the child. A full evaluation should also include a thorough interview with the child’s parents that covers general development and current concerns. The interview will also closely investigate ASD-related symptoms. To gather more information, parents might be asked to fill out special questionnaires as well. The Autism Diagnostic Interview, Revised (or ADI-R) is one such interview, and is often paired with the ADOS. However the ADI-R takes two hours to provide, making it difficult to use in clinical assessments, Dr. Epstein notes. An interview based on the ADI-R or a parent checklist, such as the Social Communication Questionnaire, can also be effective if it is led by a clinician trained in diagnosing autism. Dr. Epstein explains that it is important to include early developmental information during the interview, because there are many circumstances where symptoms are more obvious earlier, say at around four years of age, but diminish as the child grows. “If you aren’t attending to that early development and you have an eight or ten year old, for example, you’re going to risk really missing out,” she warns. Having that information about early development can help the provider make a more accurate diagnosis. If the child is of school age, it is also helpful if the practitioner can speak to the child’s teacher to get their point of view, too. A school visit to observe the child would be “absolutely ideal,” says Dr. Epstein, but not always possible. A conversation with the teacher, or having the teacher fill out a questionnaire, will give the person doing the evaluation some insight into what the teacher is seeing firsthand at school, which may be different from what parents are seeing at home.

An assessment should also include some amount of cognitive testing. One reason for this is that cognitive testing gives the person doing the assessment another chance to examine the child’s behavior, but this time under different circumstances. The ADOS is a socially loaded test that is also less structured, which might be difficult for some kids. Dr. Epstein explains that some kids will do better during a more structured cognitive test when they are answering specific questions. “Or maybe they will get upset during the cognitive testing if they don’t know the answer to a particular question, and they might have a tantrum,” says Dr. Epstein. All of this information is helpful for the person doing the evaluation. The cognitive testing is also important because you want to learn more about how the child thinks – for example you want to learn more about how the child organizes and plans, or solves problems. Beyond helping the evaluator in making an accurate diagnosis, Dr. Epstein explains, “If you don’t know their strengths and weaknesses, you can’t really contribute meaningfully to building an educational program for them at school. You want to be able to say, ‘He can do this; he can’t do that; this is what he needs to be able to do that’ (http://www.nesca-news.com/2016/05/?m=0).

In addition to the medical evaluation, it is recommended to collaborate with specialists with experience and expertise in diagnosing children on the autism spectrum. Parents can communicate and relate constructively with these specialists by conducting discussions focused on the child’s issues.

It was developed by Schopler, Reichler, DeVellis & Daly (1980) and the internal consistency of the scale seems appropriate to be considered a valid measure.

Diagnostic steps:

- determination of the cognitive level (nonverbal and verbal);
- determination of the language use ability;
- establishing behavioural correspondence with: chronological age, mental age, language age;
- establish specific problems of social skills, play, communication;
- identification of medical conditions;
- establish other relevant psychosocial factors.

There are many tools for evaluating autism. One of them is the Childhood Autism Assessment Scale (CARS). CARS was developed by Eric Schopler, Robert Reichier and Barbara Rochen Renner. It was designed to diagnose autism in children. The tool offers the opportunity to differentiate autism from other developmental delay disorders, such as mental retardation. CARS allows the evaluation of the child's behavior, characteristics and abilities.

Autism Spectrum Rating Scale (ASRS) is a set of scales built to measure behaviours associated with Autistic Spectrum Disorders occurring in children and teenagers aged between 2 to 12 years. These assessments are done either by parents or by educators, teachers, or by all of them. ASRS is an aid instrument for:

- establishing the diagnosis;
- planning of treatment;
- monitoring the response to the intervention;
- evaluating the program in which the person with Autism Spectrum Disorder was included.

ASRS contains items related to Classical Autistic Disorder, Asperger Disorder, and Pervasive Developmental Disorder without any other specification. Due to the low rate of Rett Disorder and Child Disorder, as well as due to the specific nature of their symptoms, ASRS does not contain special items for these disorders and is not addressed to them. These disorders are usually diagnosed on the basis of direct observations and child history research by specialists. ASRS for children aged 6-12 is a questionnaire comprising of 71 items describing present behaviours of the evaluated child. ASRS is built to provide information on the current / recent child's operation. When completing the ASRS, the assessor should consider the behaviour observed with the child over the last four weeks. Because they rely solely on the behaviours observed over the last four weeks, responses allow the awareness of changes in the child's behaviour over time to help monitor the outcome of the intervention and evaluate the intervention program in which the child was introduced.

The use of this four-week time interval requires that the assessor know the child for at least a month and have had enough opportunities to observe the child's behaviour. While the recognition of Autistic Spectrum Disorders has increased, the risk of underdiagnoses or over-diagnosis did too. Thus, the need for a tool to be built with care and whose results can be trusted has become essential. ASRS has been developed to meet this need. ASRS is not intended to be the only method used to establish a diagnosis, assess children or plan treatment. Evaluators are warned about making unverified interpretations. To get the most complete picture of the rated person, we recommend that this tool be interpreted by a specialist. It will corroborate the information provided by ASRS scores with information obtained from the application of other professional tools, as well as those obtained through interviews and discussions with the child, but also with other people who have information about it. There are scales that measure the most common behaviours associated with autistic Spectrum Disorders for children aged 6 to 12: Social/Communication, Unusual Behaviours and Self-Regulation. The total ASRS score is the most comprehensive score for the existence of ASD in a child. It is the average of the three ASRS scales. Even if this score is useful globally, it is necessary to interpret each of the scales individually in order to have a complete picture of the evaluated child.

3. The stages of the diagnostic process

The first step in a diagnostic process in general is to collect information about the child through a detailed clinical history, after which appropriate tests, questionnaires and tests can be applied. In the case of small children, it is recommended to join them together with their parents, to observe all aspects of the child's relationship with them, the toys, the need to initiate activities and games with others, and the reaction when parents are separated reference to the first years of life.

In the evaluation process in children with a good level of functioning is very important to evaluate them and their parents separately, following a meeting of both groups.

The following areas will be analyzed:

1. Personal data.
2. Reason for evaluation.
3. Familiar and educational context (family situation, educational situation).

4. History and dates of previous investigation (family history, pregnancy and childbirth, medical interventions, psycho-motor development).
5. Evaluation of current development (general description of observed behaviour: social development, motor, language, level of cognitive and emotional development).

All this information can be obtained by applying questionnaires and psychological tests, thus establishing an index of cognitive capacity, abilities of expressive and receptive language, etc. These include additional tests (useful but not essential in establishing the diagnosis) such as: Theories of the Mind, Functional Tests, and Psycho-Motor Development Tests. A tranquil environment and richness of details, as well as video recordings provided by parents, are important for a good development of the diagnostic process. There are also fundamental and relevant elements for establishing a differential diagnosis such as: the age of the child when parents start to worry about, the way in which language, as well as the child's communication intentions. It is recommended to consider that the symptoms of Asperger's Disorder are seen at a more advanced age due to a seemingly normal linguistic development at an early age. It is recommended to observe the three fundamental features defining the Autistic Spectrum Disorder described by Wing, L. & Gould, J. in 1979: social level difficulties, language and communication difficulties, stereotypes and limited interests. There are children with autism who do not anticipate in the first months of life the desire of parents to take them in their arms and, as a result, they do not raise their hands or change their position to help them, do not embrace their parents maintaining a rigid position. As the visual contact can be observed, it is not used to attract the attention of parents to objects of interest to the child. Some can make inappropriate social approximations without discriminating the presence of strangers from familiar ones. It can be noticed the lack of interest in dealing with children of the same age, including the absence of consciousness about their existence. Older children with a different level of development do not understand the concept of friendship and can be the target of classmates' jokes. When they are young they do not participate in social games involving emotional exchange with their parents. In general, they tend to play alone by observing the absence of functional and symbolic play in favour of repetitive and stereotype play (opening and closing the door, repeatedly turning the light on and off, observing toys from different positions, etc.). On the other hand, the communication difficulties that can be observed in Autism Spectrum Disorder are much more complex than those that require a simple speech delay and may share characteristics with the deficiencies observed in the evolutionary language disorder or the specific language disorder (Allen and Rapin, 1992). A scale can be observed that can start from total mutism reaching up to a fluid language though accompanied by semantic (word meaning) and pragmatic (communicative language use). Also, in most cases, there is a lack of understanding. For example, children with autism do not answer when they hear their own name.

When they are young they are described as very quiet babies, who do not babble and develop no verbal language. In other cases, parents speak of normal development until about 12-18 months of age, after which they notice a regression in the appearance of speech and the tendency of the child to isolate itself, which is why they asks for his evaluation. In the absence of language, there is a tendency in many cases to obtain the desired objects by pulling the hand of the parents, signalling the object by pushing the parent's hand towards it, without using any kind of vocalization or visual contact with them. If there is a fluid speech there is the impossibility to converse, understood in terms of the communication process established between two interlocutors. These children are accustomed to capturing conversation with stereotyped themes that an interlocutor has no interest into them. It is also possible to observe the presence of immediate ecolalysis (the tendency to repeat in the absence of comprehension a word or linguistic expression that he just heard) or the presence of the same type of repetition, but after hours, days or even weeks (eclipses delayed). Referring to stereotypical interests, we mention the children's tendency to repeat the same activity endlessly, upsetting at the moment they are interrupted. In the case of children with speaking abilities, attention is drawn by the tendency to ask the same thing in a repetitive form, as they know the answer, or to display fascination for the same field of interest like dinosaurs, cemeteries, airports, etc. (in the case of Asperger's Syndrome). There is also a desire to keep the order of objects in the house or to wear clothes of the same colour, to eat only a certain type of food, to go to school on the same road, to keep the family routine unchanged. They can experience stereotypical body movements such as "hands-on" when they are nervous or running side-to-side without interruption, keeping a strange posture and walking on peaks etc. Others may experience fascination with certain objects such as ropes, electric cables, doing repetitive and oscillating movements with them.

Conclusions and recommendations

According to the “Romanian Autism Study” made by e Romanian Angel Appeal Foundation, regarding the chances of recovery and integration, it is mentioned that early diagnosis and therapeutic intervention increase the chances of recovery of people with autism. Almost 50% of those surveyed believe that the social integration of people with autism is the best solution for supporting the recovery therapy, but the lack of information about the condition affects them in direct interaction with people with autism. As with all people with special educational needs and with people with autism, there is a need for an individualized approach that involves adapting the evaluation tools, but especially those of intervention to the specific particularities of each one. The paradigm of the pedagogy of the differentiated approach highlights the resources, the potential of the persons with CES, who can obtain improved results at the level of many dimensions of their personality. The Autism is still an enigma since, despite all the research done so far in this field, the causes are still unknown. The results obtained following the implementation of the individualized service plans led to significant conclusions on how to intervene and rehabilitate children with mental retardation and autism. The child with these types of deficiencies should be included in an intervention program at an early age, this work can help the child with autism develop to its full potential. Therapy should start as early as possible and take place regularly, on a regular basis.

Of all the problems that this syndrome generates, there is often a tendency to pay more attention to communication and language problems as well as to those related to behavior, but we consider that it is necessary to pay equal attention to all these aspects because they influence each other and it is preferable to be improved or recovered through a complex intervention program that targets therapeutic and compensatory activities for all aspects of personal development.

The main objective should be to general progress of the child’s reaction and action. Autism characteristics can be manifested in different ways and vary in severity. Also, changes in the behavioral evolution of the same person can be registered. Thus, the intervention programs must be adapted to the needs of each person.

Generally, children with autism best respond to well-structured interventions which, although different in content, retain a pattern, a basic structure, inducing a certain routine. Any communication skills developed during the educational activity should be generalized according to the vary situations in which the child is engaged.

A well-structured therapeutic program, based on the child's practical experiences, which includes behavioral modeling strategies and cognitive stimulation, helps children with associated deficiencies improve their communication, behavior, social skills, adaptability and learning skills, being efficient if it is practiced and continued at home. I considered that it is necessary a structured presentation of the problems which generate this syndrome both at the individual level as well as at the family level, because the number of diagnosed children with autistic syndrome is alarmingly increased and the impact of taking care of a child with autism over the family can be devastating.

Thus, another aspect that should be emphasized is the strengthening of the parent-specialist relationship, because the stronger the relationship, the more the child will have to gain. The problems that can be most difficult to alleviate are the stereotypes, because children get certain self-stimulating sensations through which they do not have doing other activities, and in these conditions, first, those creative and constructive activities must be found with which can be replacing the stereotypes, regardless of their nature. The approach based on learning theory, on operative conditioning, on the use of rewards after each success, proved to be effective in this respect. Even if there are a many techniques, methods, and intervention strategies applicable to children with autism, the best way to intervene is to combine them in proportions dictated by the child's personal characteristics.

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Treatment fads and autism spectrum disorder

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1. Introduction

Fad (https://dictionary.cambridge.org/dictionary/english/fad) is a noun that means style, activity, or interest that is very popular for a short period of time. Fad treatments are usually closely related to pseudoscience. The term "pseudoscience" describes theories and practices that seem to be logical and based on empirical research but without significant scientific support. Pseudoscientific practices can be potentially harmful and dangerous. Some of them promises and promote cure for patients with serious medical diagnoses.

Autism is a "magnet" for treatment fads (Lilienfeld et al., 2014). One review showed a list of over 50 scientifically unsupported or poorly supported interventions for autism (Lilienfeld et al., 2014). Many parents of children with ASD seek and find from 4 to 7 interventions in the same period (Green et al., 2006; Schreck, 2014, Lilienfeld et al., 2014).

Fad treatments also use scientific jargon and sound logical. Many are supported by celebrities and are promoted and discussed in media, especially internet, and therefore become accessible to public as well as parents. Fad treatments are also not scientifically proved as being effective in treating autism (Zane, Davis & Rosswurm, 2008). Furthermore, people believe in pseudoscience because they like patterns and look for evidence that confirm a theory while ignoring the evidence that disapprove it.

Parents of children with ASD are particularly vulnerable group when it comes to pseudoscience and fad treatments. After getting a diagnosis for their child parents are overwhelmed with fear. Sometimes they start with the grieving process and in stage two some parents may deny their

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child's disability or try to avoid that reality in some other way. Some parents will try to take action as an attempt to change the reality. Some may "shop for a cure" or try to bargain for a different reality (Healy, 1996). From the clinical experience of the authors, parents are told a lot of terrifying facts like autism is a lifelong condition that affects almost all areas of functioning and require substantial and life long support. Parents also connect autism with a lot of bad expressions they heard about it such as: "tragedy", "divorce", "destruction of family", "epidemic". This can cause fear about child's future and have consequences on child's life, the life of their other children, relation with partner, sustainability of their family and their own future. In that situation parents can agree to different questionable treatments. Pseudoscience statements are usually made in a way that can be applied to everybody. They also use descriptions, examples, experiences and illustration that are comprehensive, and everybody can find themselves in them. On the other hand scientific statements are often made in the way that it is too complex for parents to understand and critically analyse the results. In such materials there is not enough real life descriptions and they are also not available to average parent who is not academically educated. One study has shown that 86% of parents of children with ASD search the websites in finding autism treatments and only 44% consult journal articles (Mackintoch, Myers & Goin-Kochel, 2005).

For parents, it is easier to believe and raise hope when parents are listening ordinary, available people who are telling them their life stories and sharing with them their struggles and also giving them some theoretical basis that seem to have sense and it is communicated in more or less everyday language. Some professionals also don't know how to read and understand articles from academic journals. Unfortunately, some professionals have scientific training but choose to ignore it for professional and financial profit (Foxx, 2010). Researchers and practitioners sometimes assume that some new treatment that was proved to be ineffective will be immediately abandoned, but that is often not true. Ineffective techniques may persist long after they have been debunked (Lilienfeld et al., 2014; Paynter et al., 2019). It can also happen that some behaviors of ASD (aggression, nonverbal communication, attention) raise and fall over brief period of time. Parents but also professionals can attribute those improvements to fad treatments rather then to for example maturation of child (Romancyck et al., 2003; Lilienfeld et al., 2014).

Zane, Davis & Rosswurm (2008) state that fads provide several threats for parents. They cost parents emotionally but also financially.

Child with autism is wasting precious time in therapies that are not giving results. The worse is false hope that fad treatments give to families that are strongly emotionally involved in anything that has any chance to help their child (Zane, Davis & Rosswurm, 2008).

In Croatia, there are some very popular treatments for autism spectrum disorders, sensory integration therapy, neurofeedback and Tomatis therapy.

Each of these treatments will be presented and their scientific evidence will be discussed in the following section

2. Sensory integration therapy

Sensory integration was first introduced by Ayres (1978). She defined it as a neurological process for organization of senses from the body and the environment that enables a person to adjust the behaviour and reactions. Sensory integration is claimed to be the prerequisite for high – level cognitive functioning (Lane, 2002). It is recognized in Diagnostic and Statistical Manual of Mental Disorders 5 (DSM 5) that persons with autism spectrum disorders have different reactions to sensory input, they can be hyper or hyporeactive to sensory input or have unusual interests in sensory aspects of the environment (APA, 2013). Many authors have used the term sensory integration disfunction to describe the difficulties with sensory processing of children with different developmental disabilities (Kimball, 1993; Mulligan, 1998; Stock-Kranowitz, 1998). That dysfunction can affect integration of vestibular, visual, auditory, proprioceptive and tactile system. Since those difficulties exist, sensory integration therapy has been developed. It is a clinic-based approach which uses sensory – motor activities through the therapist – child relationship to enhance processing and sensory integration of affected systems. Parham, Chon, Spitzer and Koomar (2007) have described the key components of sensory integration therapy that include:

1. Structural preparation – rooms with sensory equipment, space for exploration and educated professional.
2. Process of intervention – providing sensory opportunities, providing just right challenges, collaborating on activity choice, guiding self – organization, supporting optimal arousal, creating play context, maximizing child's success, ensuring physical safety, arranging room to engage a child, fostering therapeutic alliance.

Sensory integration therapy is usually provided by occupational therapists although other professionals are also using it. It is usually conducted 2 to 3 times a week for 45 minutes or 1 hour in specially equipped rooms.

Ayers claims (1978) that sensory integration therapy can build a foundation on which the brain can work better. In theory, concepts of sensory integration are created on well – established neurological functions and structures. It has very extensive theoretical framework. However, a major limitation of sensory integration is the concept that sensory integration is a prerequisite of higher cognitive abilities which has no scientific basis. The fact is that functional organization of the nervous system acts as "co – occurring and interactive network of cortical and subcortical systems that mediate voluntary and involuntary responses to stimuli" (Smith, Mruzek & Mazingo, 2016: 248).

Sensory integration therapy is one of the most widely used treatment for children with autism spectrum disorder. The experience of the authors is that it is the only treatment to which most of ASD children have access to and it is also always available in state funded programs. However, till this moment there are no solid evidence about the effectiveness of the treatment nor all the available treatments that are called sensory integration therapy follow similar procedures. Numerous reviews have been conducted by different authors that used different criteria to evaluate the quality of the study and presented results. Lang and colleagues (2012) have analyzed 25 studies. Of those 25 studies, 3 concluded that SIT was effective, 8 studies had mixed results and 14 studies reported no benefit for children with ASD. Authors have also analyzed the quality of methodology of the studies and concluded that many of reviewed studies, including all 3 of those that reported positive effect had serious methodological flaws. In the conclusion they state that SIT is not evidence-based approach for children with ASD.

In another review by Case-Smith, Weaver & Fristad (2015) 19 studies were reviewed. Interventions were divided in two groups, sensory integration therapy and sensory – based intervention. Sensory integration therapy was described as clinic-based intervention that uses enrichment of the environment and chid directed activities to improve child's responses to sensory stimuli. Sensory based interventions where considered ones that used single sensory strategies in the classroom, like weighted west. Authors have reviewed 5 studies with sensory integration therapy and 14 with sensory – based intervention. They have concluded that 2 randomized controlled trials have found positive effects, and that the other studies had methodological limitations. Two randomized controlled trials that were mentioned were Schaaf et al. (2014) and Pfeiffer et al. (2011). Those are the only randomized controlled studies of SIT that will be reviewed here in more details. Schaaf et al (2014) have enrolled 32 children in their study. There were 17 children receiving SIT and usual treatment and 15 children receiving only the usual treatment. The experimental group that received SIT has acquired higher results in individualized goals, caregiver assistance in self-care and socialization according to their parents. In Pfeiffer et al study (2011) there were 37 participants. 20 children have received SIT intervention and 17 have received fine motor intervention. Participants in SIT have acquired higher results on individual intervention goals and there was a significant decrease in autism mannerisms. However, there were no differences in adaptive behavior, social responsiveness or surprisingly, in sensory processing measures. It is important to mention that studies have used parental reports and mostly not direct measurements, and in Pfeiffer et al study (2011) there were no changes in primary target of SIT, sensory processing. Both studies have included treatment fidelity measures introduced by Parham et al. (2007). Analyzing the description of components of intervention “allowing the child to actively exert some control over activity”, “arranges the room and equipment in the room to motivate the child to choose and engage in an activity”, “facilitates or expands on social, motor, imaginative, or object play”, “making changes to environment or activity to support the child’s attention, engagement, and comfort” (Parham, 2011: 219). All those procedures can be found in other intervention packages like for example incidental teaching or pivotal response training (Koegel, Carter & Koegel, 2003; McGee & Daly, 2007). Therefore, if the positive effect appeared it can be due to using elements of educational approaches that have shown effectiveness and not due to special sensory equipment, environment or sensory stimulation. Overall, it can be concluded that sensory integration therapy has limited scientific evidence and support and further research is needed to determine the appropriateness of this intervention for children with ASD.

3. Tomatis therapy

Tomatis is a method created by Alfred Tomatis, a French doctor, sixty years ago. This method is based on the idea of connectiveness between the brain and auditory information from the environment via auditory organ. Ear also has a vital role in capturing our movements, balance, coordination and rhythm. For this reason, relation between the environment and the brain the ear creates, has a great impact on numerous aspects of human in everyday life. Therefore, Tomatis is created with an idea of stimulating the brain through the auditory system in order to improve the quality of listening for children and adults. It operates through a device called TalksUp. The device modifies voice and music according to specific guidelines. It contains many features which allow swift transitions between high and low frequencies which cause the ear to have many adjustments and thus stimulate the brain. Before the beginning of the Tomatis sessions, Tomatis professional assesses clients listening abilities and creates and individual program accordingly. It's claimed to be a complementary tool which has an effect on attention, learning, voice and language, motor skills and coordination and personal development. It can help people whose disorders affect those areas of functioning like autism spectrum disorder (ASD), sensory processing disorder or Down syndrome (Tomatis Method, 2019).

Abedi Koupaei et al. (2013) reported about the effects of the Tomatis sound therapy method on the ASD symptoms of 34 autistic children between 4 and 8 years old in Teheran. The study reported possible positive impact on reduction of the autistic symptoms, increase of social interaction and reduction of autistic movements. Conclusions of this study should be taken with caution because during test runs, parents at times did not respond appropriately to the presented questions. It is also not known if the children attended some other therapies simultaneously. To conclude about success of this method on reduction of autistic symptoms, more strict and comprehensive research should be conducted.

Effects of Tomatis sound therapy on the language in children with autism were investigated by Corbett, Shickmann & Ferrer (2008). Results of their study show no significant differences on the language measures across the groups attributed to the treatment condition. All subjects in the study showed improvement in their language skills over time, but the change did not appear related to the treatment condition. Limitation of this study is a small and heterogenous sample size.

Neysmith-Roy (2001) applied Tomatis Method on 6 autistic boys (aged from 4 to 11 years) and evaluated treatment with Children's Autism Rating Scale (CARS). This research suggests a possibility of benefit of Tomatis Method on some prelinguistic behaviours of autistic boys especially when combined with other behavioural programmes. Study also has its limitations. During the research, experimental conditions were not rigorous enough. Effectiveness of a treatment was dependent on parents' perception, some of the children were previously included in some form of treatment and one boy was included in several simultaneous treatments during the research. Study suggests evaluation of effects of Tomatis Method in more rigorous research environment with controlled experimental conditions.

Thompson and Andrews (2000) reviewed theoretical foundations of the Tomatis Method and research conducted on children with learning and communication disorders. Their review reports some positive effects on different areas of functioning of children with disabilities, but also suggest additional research is necessary.

Research of the effects of the Tomatis Method on persons with ASD exists, but it is not designed in a way that could facilitate the conclusions of its effectiveness. More rigorous research with controlled experimental conditions is recommended. Therefore, to ensure the best possible way of supporting the development of persons with ASD, methods with more substantial scientific background should be used.

4. Neurofeedback

Neurofeedback is a method that uses computer technology to teach individuals to control their brainwave patterns by using operant conditioning. Electrodes that measure brainwave activity are placed on individuals head while the individual is engaged in a computer game. When he starts to control his brainwave activity, his score gets higher and he is able to progress in the game (Coben, Linden & Meyers, 2010). Neurofeedback is scientifically proven to be successful in treatment of ADHD (inattention, impulsivity and hyperactivity behaviours) (Arns et al., 2009), and therefore it is assumed that it could be successful in treatment of other disorders including autism spectrum disorder (ASD) (Coben, Linden & Meyers, 2010).

Holtmann et al. (2011) rewieved studies that evaluated effectiveness of neurofeedback when it is used as a method of treatment of ASD core symptoms. The study showed research that includes neurofeedback and ASD and may show success in treatment, but actual improvement is in comorbid symptoms of ADHD. There is no evidence on improvement of ASD symptoms as a consequence of neurofeedback treatment. This study also has its limitations connected to the reviewed studies including short duration, small sample size, insufficient control interventions, variable diagnostic criteria and lack of generalizability.

Rossignol (2009) did a systematic review of novel and emerging treatments for ASD. By using verified evidence-based guidelines, each treatment was assigned with a grade of recommendation. Neurofeedback was assigned with “Grade C” which means that method is “supported by at least 1 nonrandomized controlled trial and 2 case series”. Therefore, it is currently not scientifically approved as a method for treatment of ASD and additional research is necessary.

Effects of the neurofeedback treatment on children with ASD was investigated by Kouijzer et al. (2010). The study reported positive effect of treatment with the reduction of theta power confirmed by pre and post QEEG measures for 60% of the participants. Parents and teachers also reported positive effects on the communication skills and reciprocal social interactions. Study has its limitations. There is a possibility of bias of parents and teachers that filed behavioural questionnaires before and after the treatment. Treatment effectiveness could also be questioned by examining the difference in attention given to experimental and control group. Experimental group may have had better results because of the increased amount of attention and time they were given.

Friedrich et al. (2015) examined neurofeedback training approaches to prove effectiveness on cognition, behaviour and emotion regulation of 13 children with ASD. Treatment was based on a game that provided feedback based on emotional responsiveness and imitation and encouraged social interactions. Study reports improvements in electrophysiology of brain expressed as increased mu suppression, emotional responsiveness and better behaviour in everyday life. Conclusions of this study need to be considered with caution because of its significant limitations. Study had a small sample size and participants were included in other treatments during the study. As it was reported, 9 out of 13 children were included in occupational therapy, applied behaviour analysis, music therapy, speech therapy, cognitive behavioural therapy, Son-Rise therapy, real opportunities for independence therapy, adaptive physical education or social skill practice at school. Results of the study could also be influenced by interaction between the children and the staff during therapy sessions.

More recent study conducted by Carrick et al. (2018) investigated effect of neurofeedback method using novel Mente Autism device tool on modulation of brain activity that could result in modification of the behaviour of children with ASD. Study had 34 subjects (17 Active and 17 Control) and results showed improvements of the experimental group in areas of brain activity, behaviour and sensorimotor behaviour. Despite of positive results, study suggested further research should be conducted due to several constraints. Large drop out rate in post treatment condition was reported, there were challenges in standardization of testing procedures due to behavioural characteristics of children with ASD. Generalization to a larger population could also be questionable because of the study being conducted in specialized neurological clinic. During the study, participants were included in other therapies that could have influenced the results of this study.

In conclusion, although neurofeedback method is proven to be effective on ADHD symptoms, there is still no substantial scientific evidence that it has the same effect on the ASD symptoms. Further research with better experimental control and more rigorous methods should be conducted.

These short reviews have shown that 3 most popular treatments don't have sufficient evidence of effectiveness for children with ASD and yet they are widely used and also recommended by professionals. Professionals are the ones that have to help parents in selecting the best treatments for their child and also empower them to make informed choices themselves.

5. Suggestions for professional while supporting parents in choosing best treatment for their child with ASD

Considering the complex nature of ASD and parents' perspective and context it is easy to understand strong need of parents for searching numerous treatments and the most effective and fast solution for their children. Due to their fear and hope for recovery parents are trying all sorts of proven and unproven treatments. They also hope that their child is misdiagnosed or savant with unrealised potential (Paynter et al., 2019). The role of parent is to hope for miracle for their children. But what is the role of professionals in leading and supporting parents in the process of finding the best possible treatment for their children?

It is important that professionals lead parents in the way to choose empirically validated treatment.

After finishing assessment professionals must explain parents why the child is meeting the criteria for the diagnosis and why particular treatment is recommended. It is important to give parents reliable resources in which they can check efficacy of treatment. They need to direct parents in choosing treatments with arguments in favour of the best solutions (Kay, 2016). It is very important to be specific in giving information. Professionals should work together with parents in targeting problems and behaviours of child with ASD that need to be improved and treated. Common agreement will help parents to trust more in professional and to give them a sense of control in this stressful situation. Professionals agree with parents about the data collection procedures and evaluating the effects of treatments. It is important to show, discuss and interpret the effectiveness of the treatment for the child.

Authors Celiberti, Buchanan, Bleecker, Kreiss & Rosenfeld (2004) in accordance with McDonald, Pace, Blue & Schwartz (2012: 300) suggest some key questions for parents and professionals that can help them in considering the right treatment:

1. First and foremost, what research is available in the professional literature that confirms the effectiveness of this approach? Is there a research that does not support the effectiveness of this approach?
2. Does the published literature represent objective, empirical research (i.e., scientifically driven and data based)? Or is it descriptive research that describes someone's impressions over time?
3. What areas of functioning and specific behaviors are being targeted by this approach? In other words, how exactly will this treatment affect your student/child with autism?
4. Are there adverse effects associated with this treatment approach?
5. Are there schools and agencies utilizing this particular approach that are committed to science-based treatment?
6. Does every individual with autism receive the exact same treatment? If not, how will this treatment be individually tailored and based on what factors? In other words, how can this treatment approach be adjusted to meet the needs of your student/child?
7. What baseline data are requested by the service provider? Does the service provider discuss ongoing data collection?
8. How will the success be measured?

If parents have trust in professionals, they will share alternative options they have heard about and question professional about it. Professional should respect parents right for his or her own opinion and for their right to make decisions for their children regarding treatment. However, professionals must explain that scientific evidence and the use of objective data should guide treatment options. If parents decide to try alternative treatment professional can proceed with his or her work with child and possibly help to collect data and evaluate alternative treatment. If parents insist on using treatments that are harmful for children professional can refuse to work with child (Kay, 2016).

It is very important for professionals to improve their knowledge about evidence-based treatments and keep themselves up to date with fresh data. Furthermore, it is also important to improve their ability to communicate with parents and develop creative approaches in educating parents as well as encouraging self-directed learning. It is better not to stick just on trying to exterminate misunderstanding but to give parents something else to believe in.

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Language and communication difficulties in Autism Spectrum Disorder

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Introduction

Autism spectrum disorders refer to a cluster of disorders characterized by various degrees of social isolation, communication difficulties, and preference for sameness/peculiar and repetitive behaviors. Although all these characteristics are intimate interlinked and share similar brain and cognitive functioning specificity, this chapter insists on communication and language disorders. It will investigate the communication and language peculiarities of people with ASD and their implications for effective interventions. The efforts to develop and implement efficient strategies and techniques to work with people with ASD should begin with careful assessment of their particular developmental profiles and their gennuine needs (Luștrea, Al Ghazi & Borca, 2017).

1. Communication, language and speech[1]

As a general term, communication refers to transmiting and recepting information. In this process, the following elements are necessary: a sender, a receiver, a message, an intention, and a shared communication channel or medium. Communication has three main functions: instrumental (achieving desirable ends), social (connecting with others), and expressive (expressing own's thoughts and emotion) (Bogdashina, 2005).

Communication can be non-lingvistic (body language, gestures, facial expressions) or lingvistic (spoken/written language, sign lan-

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guage). An intremediate ways of communication are the paralingvistic ones: volume, pitch, intonation of speech or graphological aspects of written language.

Persons with ASD might have difficulties in all these type of communication. Along with impaired lingvistic and non-lingvistic difficulties, children with ASD have difficulties in imitation and imaginative play, categories of behaviors labelled sometimes as social deficits and other times as communication deficits, according to APA (2000) and WHO (1992). For efficient assessment and intervention, some studies suggest that all these behaviours should be considered social communication aspects (Moldin & Rubenstein, 2006).

Language can be defined as a conventional, structured system of communication, based on agreed use of nuclear units (phonemes, graphemes or signs) and of a set of combination rules, by a group of people. Using a system of symbols and rules of combinations, language is one of the best ways of communication, due to its flexibility, expressivity and efficiency (Bogdashina, 2005). Language, as form of communication, is both receptive (receiving, decoding, and understanding the message) and expressive (using words, spoken or written, to express your own mental state, thoughts, emotions, etc.). The process of acquiring and using human language depends on the development and functioning of diferent antomical structured, which evolved and specialyzed, along our philogenesis, in consuming and producing language (cortical and subcortical structures, sensorial receptors, vocal cords, and motor articulatory elements) (Lieberman, 2002).

Human language, as well as other complex human behaviors as walking, thinking and reasonning, are regulated through neural circuits from subcortical structures and neurocortex. Liberman (2002) affirms that the traditionalist locationist brain model (the Broca-Wernicke/Gerschwind model), from the beginning of 19th century should be replaced by the circuit models.

Current studies and knowledge in neurophysiology support the thesis of computational structure of biological brains, and neurophysiological activity is better explained as a two levels operation. Thus, although is a comun evidence that complex behaviors are regulated in particular parts of the brain, but not in themself. They could not regulate alone these behavious, but these specialyzed "populations" of neurons, which carry out local process or processes, are linked or "project" to neuronal populations from other neuroanatomical structures (Poeppel et al., 2012; Lieberman, 2002). Through these successive links form a neural "circuit" – the brain basis of a complex behavior (Lieberman, 2002).

This "circuit" model are sustained by clinical observations (studies on aphasia, Parkinson's disease, hypoxia, and so on), where the type and severity of the impairement and the rehabilitation depend by the different localisation of damage (cortical and/or subcortical). Persons with ASD seem to present reduced activation and connectivity in frontotemporal network specialyzed for language, less functional lateralization for language or the tendency for right emisphere dominance (Mody et al., 2013).

Cortical and subcortical structures have the role of decoding a message received via auditory (for spoken words) or visual (for written words) receptors (receptive language), and also the role of comanding and regulating the activity of vocal cords and articulatory system (for speech) or of the hand (graphia) in generating the response (expressive language).

Receptive language develops prior to expressive language, that is we understand the speech of another person before we are able to speak.

Speech, the ability to speak, refers to spoken, expressive language.

Recent studies suggest that even the paradigm of stable functional language network become obsolete and limitative, and should be explored the hypothesis of a dynamic and contextualyzed networks reconfiguraton during language comprehension (Hasson, Egidi, Marelli & Willems, R.M., 2018). Agreeing with the assumption that ontogenetically and phylogenetically, the urge to communicate precedes linguistic abilities (Liszkowski, 2011; Tomasello, 2003), language being a highly efficient code for this purpose, Hasson et al. (2018) consider the importance of context in comprehension and advocate for a new neurobiological non-language-centered conceptual framework, which better explain the connections between language and other cognitive systems. They highlight the impact of multiple contextual characteristics in integrating and comprehending the incoming language contents.

2. Characteristics of language and communication in ASD

It is well-known and documented that the core features of ASD are social and communication difficulties (Al Ghazi, 2018; Gernsbacher et al., 2017; Moldin & Rubenstein, 2006).

What differentiate mostly the communication deficits of children with ASD is the lack of social communication, such as gesture, increased eye contact or atention to others' facial expression, to compensate for language delays. The most representative characteristics of social communication deficits in person with ASD are the lack of reciprocity and joint attention (Moldin & Rubenstein, 2006; Lord & Corsello, 2005; Baranek, 1999; Mundy & Sigman, 1989).

At pre-linguistic period, babies use non-verbal communicative behaviors (such as crying), which are easy to understand and to interpret by their carers. Children with ASD seem to have difficulties in developing these conventional non-verbal communicative behaviors.

While aproximately 25% of persons with ASD never develop language, majority of children with ASD present delays both in receptive and expressive language (Charman et al., 2005), as well as children with other developmentally disorders. The presence of speech before the age of 5 is considered a good predictor for better evolution of language development in persons with ASD (Mody & Belliveau, 2013). Also, persons with ASD present problems in all aspects of language: prosody, phonology, semantics, syntax, and grammar.

For many years, even from the first enter in the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders* in 1980 (DSM-III, APA 1980), an important criteria for autism diagnostic was "gross deficit in language development" or "peculiar speech patterns", such us echolalia, metaphorical language, and pronominal reversal.

In the following editions of DSM (DSM-III-R, APA 1987, DSM-IV, APA 2000; DSM-IV-TR, APA 2004), this criterion was modified (Gernsbacher et al., 2017), echolalia and pronoun reversal becoming optional, and metaphorical language being consider idiosyncratic language. The latest edition of DSM (DSM-5, APA 2013) do not mention pronoun reversal and delay in language development as criteria, and echolalia and idiosyncratic language are considered possible "restricted, repetitive patterns of behaviors, interests, or activities".

Gernsbacher et al. (2017) presents evidences that these peculiar communication phenomena are not unique to autism, they manifest also in typical developed children, children with language delay, children with intelectual disability, therefore they shouldn't serve as diagnostic criteria for autism.

Lately, in the 90', researchers became interesting in an another particular phenomenon in speech and language development, which seems to be unique and specific for children with ASD: the surprising abnormal comprehension versus production lag (Cohen & Volkmar, 1997, cited by Gernsbacher et al., 2017). While, in typical language development, comprehension (receptive language) is always superior to production of language (expressive language) (Fenson et al., 2007; Schmitt, 2008; Pilulski & Templeton 2004; Benedict 1979, cited by Gernsbacher et al., 2017), some studies suggested that this logic and quasi-universal rule doesn't apply to ASD. Instead, some researchers claim that this lag between language comprehension and language production is reduced in the case of children with ASD, or doesn't exist (Goodwin et al., 2012; Ellis Weismer et al., 2010), or is even reversed (Maljaars et al., 2012; Hudry et al., 2010).

Even though is plausible a reduction of lag between comprehension and production of language in children with ASD, the total lack of this phenomenon or the reversed situation imply a hard-to-believe model of language and speech acquisition (Gernsbacher et al., 2017). A meta-analisys of over 60 studies (Kwok et al., 2015) confirmed that the language development of children with ASD presents a normative relation between language comprehension and language production. So, an abnormal comprehension-production relation in language acquisition is, also, not a valid diagnostic criterion.

Gernsbacher et al. (2015) consider that language development in ASD may be delayed, but is not deviant.

3. Implications for interventions

Magyar (2011) classifies specific therapies for ASD in four major types, based on the their underlying theoretical models:

- behavioral (such as Applied Behavior Analysis-ABA, Verbal Behavioral Therapy-VBT, Cognitive Behavioral Therapy-CBT or Discrete Trial Training-DTT);
- developmental DIR method (Floortime) - Developmental Individual Difference Relationship;
- milieu teaching (Relationship Development Intervention);
- therapeutic (Occupational therapy, Sensory Integration Therapy, Speech-Language Therapy, Physical Therapy).

Examples of combined approaches are SCERT model and Spell approach.

Using two dimensional (type of environments and type of intervention) model of interventions, Predescu et al. (2018) advocate for an ecological holistic approach, who should aim to coordinate multiple actions at different levels of child's life.

It is obvious that efficient therapies for children with autism should focus on developing social communication, both non-linguistic and linguistic.

Conducting a meta-analysis on researches on autism which used and tested instruments promoting augmentative and alternative communication, Lima Antão et al. (2018) conclude that these instruments improve communication process children with ASD.

MacDonald (2004) highlitghts the idea that social learning requires much more than language, and efficient communication requires stable relationships and appropriate responses to immediate natural learning. He insists in acknowledging, respecting and profiting of child's actual developmental stage undergone through becoming a real and efficient social and communication partner: interactive play, nonverbal communication, social language, conversation, and civil behavior. Understanding a child's own special way of relating to the world represents the key for social and communication learning.

Conclusions and recommendations

Even though we do not know (yet) the language of another person, it doesn't mean that we cannot communicate. Even though the other person doesn't speak or communicate like us, it doesn't mean she do not speak and do not communicate at all.

Communicating with another person do not imply with necessity that the only solution is to teach her our language or ways of communication. When we meet a new foreign person of witch language we do not know, we can still communicate with her, either using non-linguistic communication or collaborating for learning each other's languages.

In traditional therapies for person with special needs, the emphasis and the effort are on "fixing" incorrect "language" and teaching "correct" or "mainstream" language or ways of communication.

We consider that it is better to begin and to conduct this process of acquiring mutual understanding and reciprocal communication, with mutual respect and collaboration, till we reach the common ground.

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The maladaptive behaviors in the Autism Spectrum Disorders. Guidelines for the evidence-based educational intervention

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1. The Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) currently represents a share of complex developmental disabilities. The increase in their incidence in the school population justifies the need for adequate responses, on the part of the training systems, to the specific educational needs from them presented (APA, 2013; CDCP, 2014). The advent of the Evidence Based Education (EBE) perspective, according to which the dissemination of educational practices must be guaranteed, whose effectiveness has been validated according to experimental procedures, has significantly influenced the research and implementation of educational models ‘social inclusion of students with Autism Spectrum Disorders (Schreibman, 2005; Guldberg et al., 2011; Fein et al., 2013; Cottini & Morganti, 2015).

In recent times, there has been a progressive abandonment of educational approaches whose effectiveness is considered doubtful or minimal, in favor of models based on experimental evidence, and in particular, those validated on experimental designs that provide for comparison between the performance of a group experimental and control group (Hammersley, 2007; Matson, 2014). Respect for this condition, according to the perspective of Evidence Based Education, is one of the fundamental paradigms for verifying the effective effectiveness of an educational intervention, in analogy with the methodologies for verifying the chemotherapeutic or psychotherapeutic interventions that have long been used in biomedical and psychoeducational approaches. (Chambless & Hollon, 1998; Odom et al., 2005; Hammersley, 2007; Chaby et al., 2012).

Despite the debate behind the opportunity to consider the effec-

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tiveness of educational practices on the same level as the effectiveness of pharmacological intervention, it is likely that the selection of educational approaches based on their effectiveness in the promotion of adaptive behavior will progressively influence the educational interventions aimed to social inclusion of students with ASD. The Autism Spectrum Disorders may represent an effective example of complex developmental disability involving the mobilization of educational, health and family resources (Parsons et al., 2011; Fein et al., 2013), f the modification of maladaptive behaviors that hinder the development of prosocial skills and personal autonomy (Odom et al., 2010; Flynn & Healy, 2012; Fein et al., 2013).

For this reason, in this chapter a brief review, of the educational intervention models for the reduction of maladaptive behaviors is presented, and his implications for the Special Education of child with ASD are discussed.

2. The maladaptive behaviors in the Autism Spectrum Disorders

Autism Spectrum Disorders have recently been redefined in the *Diagnostic and Statistical Manual of Mental Disorders-DSM 5* (APA, 2013). The criteria of the DSM 5 are based on two indicators, represented by the deficits of social communication and by the restriction and repetition of behavior.

The criteria for the communication deficit are presented in Tab. 1.

Tab. 1. Diagnostical criteria for the ASD (APA, 2013)

Communication deficit

a. Abnormal social approach. Reduced interest in the sharing of interests and emotions.

b. Deficit in non-verbal behaviors used for social interaction. Abnormality in eye contact and body language. Deficit in understanding and use of non-verbal communication. Absence of facial expressiveness and gestures.

c. Deficit in the development and maintenance of appropriate relationships. Difficulty in regulating behavior with respect to different social contexts. Difficulty in sharing imaginative games and making friends. Apparent lack of interest in people.

Restriction and repetition of behavior

a. Language, motor movements or use of stereotyped or repetitive objects. Presence of motor stereotypies, echolalia or repetitive use of objects.
b. Adherence to the routine with excessive resistance to changes.
c. Fixation in restricted interests with abnormal intensity. Excessive attachment or concern for unusual objects.
d. Abnormal interests with pervasive manipulation of objects and attraction towards lights or rotating objects.
e. Alterations of reactivity to sensory stimuli, with apparent indifference to heat, cold and pain.

The severity of the disorder is represented by a three-level scale (*Relevant, Mild and Moderate*), which represents the function of the amount of support required by the environment (APA, 2013).

The analysis of the criteria makes it possible to understand the significant role of stereotyped behaviors in the alterations of the Autism Spectrum, given that they are connect to many indicators. The repetitive behaviors and maladaptive behaviors represents a significant proportion of the behavioral profile commonly associated with the disorder, and it is evident that their pervasive presence can to hinder the adaptation of the student with ASD to social, educational or domestic contexts (Murphy et al., 2009; Mulligan et al., 2014). The presence of stereotyped behaviors seems to represent a peculiar characteristic of Autism Spectrum Disorders. The maladaptive behaviors are present in other cognitive disabilities, but the typical behavior profile associated with ASD is influenced in a massive way. This data is evidenced by studies based on the comparison with other types of intellectual disability (Bodfish et al. al., 2000; Rapp & Vollmer, 2005; Langen et al., 2011a; Boyd, McDonough & Bodfish, 2012). Despite the difficulties related to estimate of their incidence can considerate the data reported by Murphy et al. (2009) can to be considered. In the study, conducted on a sample of 157 children with ASD, is possible to consider how the 72% of children with ASD present stereotyped behavioral repertoires.

The repetitive behaviors involve various areas of behavior of the student, resulting in the form of vocal stereotypies and perseverative language, with the presence of repetitive questions and, sometimes, incessant discussions in the finality. Behavioral patterns of manipulation are common with objects of specific interest, and are commonly associated with the hand shaking, with the body rotation and with the facial rubbing (Murphy et al., 2009; Sigafoos et al., 2009; DiGennaro Reed, Hirst & Hyman, 2012; Mulligan et al., 2014). In ASD with low cognitive functioning, similar behaviors can represent the child's main activity, with evident negative effects on his communicative competences and on the understanding of environmental issues (Rapp & Vollmer, 2005; Sigafoos et al., 2009; Boyd, McDonough & Bodfish, 2012, DiGennaro Reed, Hirst & Hyman, 2012). There are present significant elements of self-injurious behavior, which can to represent a risk factor for the personal safety of the student (DiGennaro Reed, Hirst & Hyman, 2012; Mulligan et al., 2014).

The debate on the causes and functions of stereotyped behaviors in the disorder involved numerous authors who indicated various environmental, neurological and pharmacological explanatory factors (DiGennaro Reed, Hirst & Hyman, 2012; Mulligan et al., 2014). In this perspective, a significant role is played by the *social deprivation* and by *poor environmental stimulation contexts* (Rapp & Volmer, 2005; Langen et al. 2011a; 2011b; Mulligan, 2014).

The development of repetitive and limited behaviors is observable in fact in animals confined in poor environmental contexts with low levels of environmental stimulation (Langen et al 2011a). Similarly, the children born in the socially deprived environments (Langen et al., 2011b), are significantly involved in stereotyped motor behaviors, as originally observed by Spitz (1945) in his pioneering study on hospitalized children.

The role played by *physiological stress* is considered a factor capable of favoring the interpretation of stereotyped behaviors. High levels of stress con to increase the frequency of repetitive behaviors, both in the animals and in the human beings (Rapp & Vollmer, 2005; Langen et al., 2011b). The involvement in stereotyped behavior could so be considered as a consequence of the high levels of stress to which the child with ASD is subjected, especially in cases of changes in his daily routine (Rapp & Vollmer, 2005).

Alternative interpretations are present, according to which the involvement in the stereotypies could provide the child reinforcements, derived from the increase in the cardiac frequency. The motor stereotypies, in other words, could be used by the child with ASD for the search for states of well-being and activation following the increase in his heart rate (Lydon, Healy & Dwyer, 2012; Mulligan et al., 2014). An ulterior line of interpretation is connecting to the role of *neurochemical mediators* involved in the production of stereotypies. The intake of dopaminergic drugs is able to increase stereotyped behaviors in animals, while the injection of dopamine agonist decreases the frequency of behaviors of such order (Langen et al., 2011a; Langen et al., 2011b).

Finally, the role of the explanatory factor represented by the *Applied Behavior Analysis – ABA* (Lovaas, 1987) must to be considered for the understanding of stereotyped behaviors in Autism Spectrum Disorders. A similar perspective, derived from the Operating Conditioning Theory, may result in a better understanding of the function of repetitive behavior through consideration of the *reinforcement* provided to child. The ABA approach should not be considered as a model of specific intervention, but rather a research program aimed at identifying the factors that motivate behavior (Lovaas, 1987;1993). The identification of motivating factors is preliminary to the adoption of interventions aimed at modifying behavior, even if frequently this preliminary analysis is omitted (DiGennaro Reed, Hirst & Hyman, 2012; Matson et al., 2012; Mulligan et al., 2014).

The information obtained from the behavioral analysis allows to identify the maladaptive behavior, and to replace it with adaptive behaviors, based on the development of the communicative competences of the child with ASD. The ABA approach is particularly significant for educational interventions aimed at students with ASD with low cognitive functioning associated with maladaptive behaviors (Matson et al., 2012; Mulligan et al., 2014; Cottini & Morganti, 2015).

The ABA approach results based on the research of the factors that influence the maintenance of non-adaptive behavior. The analysis processes of the antecedents and the consequences of behavior are decisive, and confirmed the needs of contextual analysis of the environment in which the target behavior of the 'intervention. Similarly, the identification of the context, the structure of the episode and the people involved in the event is decisive for the identification of the functions of each maladaptive behavior (Lovaas, 1987, 1993; Cottini, 2011; Matson et al., 2012). The approach, so, is oriented towards the teaching of specific skills for the improvement of communication and for the replacement of maladaptive behavior with other more adaptive, through the teaching of socially shared modality of requests. The verbal or motor maladaptive behavior acts, is maintained in the student's repertoire cause of the automatic reinforcement produced by it. Must to be considered, moreover, the consequences on the social environment, such as those represented by the research of attention of the interlocutors of the child (Lovaas, 1987; 1993; Boyd et al., 2012; Wilke et al., 2012).

3. Evidence Based Models for Educational Intervention in Stereotypies

The perspective of Evidence Based Education is characterized by the need for empirical validation on the basis of comparisons between the pre- and post-training scores of experimental groups and randomly assigned control groups (Chambless & Hollon, 1998; Odom et al., 2005; Hammersley, 2007). One of the first attempts to develop a hierarchical model of the effectiveness of educational models for Autism Spectrum Disorders according to the EBE approach is attributable to Schreibman (2005).

According to this study, the numerous models of educational intervention developed in the last decades can to be grouped into four great macro categories, summarized in the Tab. 2.

Tab. 2. Macro-Categories of interventions for the ASD
(adapted from: Schreibman, 2005)

I. Behaviorist perspective (ABA, DTT, PRT)
II. Various theoretical models (AAC, PECS)
III. Psychodynamic interventions
IV. Pharmacological and nutritional factors

In the first macro-category all intervention programs derived from the *behaviorist perspective* are considered. In this grouping are present the models that have shown the presence of higher levels of effectiveness based on experimental evidence (Odom et al., 2005; Lequia, Machalicek & Rispoli, 2012; Fein et al., 2013; Mulligan et al., 2014). This macro-category includes both the models based on the ABA approach (Lovaas, 1993), and those derived from this perspective. The *Discrete Trial Training- DTT* (Lovaas, 1987), the Denver Model (Rogers, 1996) and the P*ivotal Response Training - PRT* (Koegel, 2000), are characterized by high levels of effectiveness for the change of maladaptive behaviors.

The second macro category of models includes the programs derived from different theoretical models. The programs derived from the *Alternative and Augmentative Communication - AA*C (Beukelman & Mirenda, 2013) and from the *Picture Exchange Communication System - PECS* (Bondy & Frost, 1994) are the most significant. These programs present objectives relating to overcoming of the communication deficit through the improving of the understanding of social stimulation. The reduction of the maladaptive behavior is strictly related with the acquisition of communication skills. Although these interventions have not yet been validated according to the EBE perspective, their significant role in the reduction of stereotyped behaviors is presumably.

The development of communication skills, in analogy with the ABA perspective, would make marginal the reference to the maladaptive behavior, given that the result related to the attention request. The request can to be achieved through verbal request or through the indication of a symbol, rather than with the maladaptive behaviors (Wetherby & Prizant, 2000; Mirenda & Iacono 2009). The recursive reference to the systems of Alternative and Augmentative Communication in the systems of international guidelines for the treatment of the disorder (SIGN, 2007; ISS, 2011; BPS, 2012) demonstrates their presumable efficacy in the reduction of repetitive and stereotyped behaviors.

The third macrocategory includes the *psychodynamic interventions,* which have enjoyed wide popularity until the Nineties, but which currently seem to play only a documentary role for the reconstruction of the stages that have characterized the evolution of interventions (Schreibman, 2005; Fein et al., 2013). The interventions of this order are mainly documented by individual case studies, which do not meet the empirical validation requirements required by the EBE perspective.

The fourth macrocategory are finally related to *pharmacological and nutritional factors*, according to which the disorder would be caused by pharmacological or nutritional factors (Schreibman, 2005). The effectiveness of nutritional interventions is presumably doubtful, while pharmacological interventions transcend the limits of the present study, which is based on the analysis of educational models. However, from the perspective of Schreibman (2005), the pharmacological interventions are also documented by individual case studies, and his efficacy lack of experimental evidence (DiGennaro Reed, Hirst & Hyman, 2012; Mulligan et al., 2014).

4. Models based on the antecedent

According the recent reviews, a determining role for the reduction of behavioral stereotypies in Autism Spectrum Disorders is that covered by Applied Behavior Analysis interventions, and in particular by those integrated by the preliminary analysis of repetitive behavior functions. The review by DiGennaro Reed, Hirst & Hyman (2012), in particular, is based on the analysis of the studies on the effectiveness of the interventions conducted from 1980 to 2012, while the review by Mulligan et al. (2014) analyzes the results of 71 studies conducted from 1990 to 2014.

The criteria used by Mulligan et al. for the definition of effective treatment they are based on the selection of studies that used standardized assessment scales for the detection of the intensity and frequency of motor stereotypies, and that used samples with at least one subject with ASD. The evaluation of the effectiveness of the interventions was calculated based on the percentage of repetitive behavior reduction. For to be considered effective, an intervention must have led to a reduction of at least 50% of the frequency / intensity of the stereotypies (Mulligan et al., 2014).

Based on these analyzes, the intervention models characterized by the highest levels of effectiveness for the treatment of behavioral stereotypies were identified. A large proportion of the models is attributable to the ABA approach, as originally conceived by Schreibman (2005) and confirmed by the recent meta-analyzes (Rapp & Vollmer, 2005; Boyd, McDonough & Bodfish, 2012; DiGennaro Reed, Hirst & Hyman, 2012); Mulligan et al., 2014).

The most effective models for the reduction of the stereotypical maladaptive behaviors are those based on antecedent treatments, the analysis of consequences (*Consequence - Based Treatments*) and those based on the teaching of skills (*Skills - Based Treatments*). The intervention models related to the analysis of the antecedents represent one of the main areas of intervention of the ABA approach. They are characterized by the preliminary analysis of the functions of the stereotypy and by the modifications of the educational context (Matson et al., 2012; Wilke et al., 2012).

The manipulation of the environmental context according to guidelines provided by the analysis of the factors prior to the development of non-adaptive behavior is in fact one of the main factors able to affect the issue of stereotypy. An example of intervention based on the antecedents is represented by the modification of the context based on the enrichment of stimulations, through the free access to student's favorite reinforcement, like toys or objects of specific interest. The continuous access to the preferred stimuli allows identifying the elements that possess the same reinforcing capacities of the stereotypies. The interventions based on interrupt and response redirection techniques (*RIRD, Response Interruption and Redirection*) can be inserted in this interventions, cause them allows the interruption of the vocal or motor stereotypy and its replacement by exercises on the social rules based on the request of objects (Ahearn et al., 2007).

In the literature, the meta-analyzes identified six studies, mostly based on the analysis of single cases, which demonstrated significant reductions in stereotypies through interventions based on antecedents (Boyd, McDonough & Bodfish, 2012; Mulligan et al., 2014).

The study of greater relevance is that of Ahearn et al. (2005), in which the techniques of continuous access to objects of interest were applied with two students with ASD of 11 and 13 years of age. The results showed that the identification of an object that presents the same reinforcing properties of the stereotypy could to favor the reduction of maladaptive behaviors (percentage of reduction of the stereotype: 78.04%). The relative ease of exporting the technique in educational contexts of the Primary or Secondary School of our country should be noted. The regulation of the access to the objects of specific interest of the student could represent a basic component of the educational strategies for the students who present evident motor or verbal stereotypies.

The study conducted by Sidener et al. (2005) is representative for the interventions based on the analysis of the antecedents. In this analysis, the authors identified a stimulus capable of competing with the functions of stereotypies in two 6-year-old girls with severe ASD. The stereotypies were represented by continuous scratching of the surfaces of the doors and walls. In this case the technique used was that of environmental enrichment: in the room were placed toys identified able to compete with the stereotypies. The continuous access to toys resulted in a significant reduction in stereotypies observed in both participants (percentage reduction of stereotypy: 67.45%).

The environmental enrichment technique could also present opportunities for the inclusion of Primary School. The teacher could create a hierarchy of the student's favorite objects, activity or toys and place them in the classroom so that they are easily visible and researchable. During the intense manifestation of stereotypy, the objects could be indicated or even presented to the student by the teacher or by the peers (Sidener et al., 2005).

Finally, we can to consider the analysis conducted by Love et al. (2012), in which the interruption and redirection techniques RIRD were applied on two 8 and 9 year-old child with ASD associated with vocal stereotypies. In this study, the RIRD techniques were combined with the continuous access to the preferred stimulations. The continuous access to toys was allowed to children; when the vocal stereotypy appeared, the teacher removed the toy and called the student with his name, involving him in a process of questions and answers. The combination of RIRD techniques with those of continuous access to the preferred stimulations resulted in significant reductions in stereotypies in the participants (percentage reduction of stereotypy: 67.45%).

5. Models based on the consequences

The main meta-analyzes conducted on the topic have identified 10 studies based on the analysis of the effects of interventions carried out according to the analysis of the consequences (DiGennaro Reed, Hirst & Hyman, 2012; Mulligan et al., 2014). The interventions considered are those related to the use of the techniques of interruption and reorientation of the response (RIRD) and on the *Cost of the Response*. The RIRD techniques have been developed by Ahearn et al. (2007); they presuppose the involvement of a teacher who presents questions in line with the verbal repertoire possessed by the student, when the verbal or behavioral stereotypes appear, until the child responds consecutively at least three times to the questions instead of using the stereotype. Each correct answer is immediately follows by the teacher's approval (Ahearn et al., 2007; Love et al., 2012).

In the experimental design originally developed by Ahearn et al. (2007) for the application of RIRD techniques, significant reductions in vocal stereotypies were observed in a sample of four children with ASD with a mean age of 7 years. The experimental design included the interruption of the vocal stereotypies as soon as they appeared, and the teacher's involvement in vocalizations that included the participant's name and the reference to simple questions to which the child was considered capable of responding (For example: *What is this? What is my name?*). The appropriate responses followed immediate behaviors of social approval from the teacher. The results indicated a significant reduction in the vocal stereotypies in all subjects, and an increase in the appropriate vocalizations for three of the four participants. The rate of reduction in stereotyped behavior ranged presents a mean of 81% (Ahearn et al., 2007).

In a subsequent study (Ahrens et al., 2011) the use of RIRD techniques was performed on two 4 and 6 year-old children with ASD associated with verbal and motor stereotypies. The participants were subjected to a preliminary alternative treatment, in order to verify the difference with the experimental treatment. In this study, the redirection occurred through two modalities: *vocal redirection* and *motor redirection*. The voice redirection consisted in the involvement of the child in the vocalization, while the motor redirection consisted in stopping the stereotype through the involving of the child in simple motor exercises. Both methods were effective for the reduction of stereotyped behavior. In particular, the motor redirection was more effective for the reduction of verbal stereotypies (percentage of reduction of stereotypy: 94.11%) compared to motor stereotypes (percentage of reduction of stereotypy: 80.47%). The vocal redirection, instead, presents the same effectiveness both for the reduction of the vocal stereotypies (percentage of reduction of the stereotype: 86.28%), and for the reduction of the motor stereotypies (percentage of reduction of the stereotype: 86.45%). The comparison with the preliminary alternative treatment also showed a significant difference in favor of RIRD techniques (Ahrens et al., 2011).

The possibilities offered by RIRD techniques could therefore be considered in the development of individualized educational programs for students with ASD characterized by the massive presence of vocal stereotypies. The teacher could remove the toy or the object of interest when the student is massively involved in the stereotypy, call it by name and try to involve him in dialogic processes. The toy or object of interest may be provided when the vocal stereotypy decreases. The RIRD techniques present other opportunities, in addition to the decrease in stereotypy. They may be able to stimulate the functional communication skills (Ahearn et al., 2007; 2011; Love et al., 2012; Mulligan et al., 2014).

In the study conducted by Liu-Gitz & Banda (2010), the techniques to reduce the response were applied in a naturalistic context represented by the class in which a 10-year-old student with ASD was included. As soon as the student issued the verbal stereotype, the teacher interrupted him immediately (*interruption*) and asked a question (*redirection*) in line with the student's skills (for example: *What did you do last summer?*). During the RIRD intervention, the vocal stereotypies showed a decrease from 41% to 10%. In this study the interruption and redirection technique favored a high reduction of vocal stereotypies (percentage of reduction of the stereotype: 96.79%).

The study by Anderson & Le (2011) has instead evaluated the effects of the *Cost of the Response* in a 7-year-old child with ASD and massive vocal stereotypies. The technique involves the removal of a reinforcing stimulus (for example, listening to music or watching a video) when stereotypy occurs. Despite the absence of a recording of the initial baseline level, the use of music has not proved effective for the reduction of stereotypy, while the interruption of video viewing has proved effective for the decrease of its frequency.

6. The capacity-based approach

The models of educational intervention based on the teaching of skills represent an ulterior family of techniques derived from the Functional Analysis of Behavior for the decrease in stereotyped behaviors and for to improve the functional communication skills. It is evident their relevance for the educational intervention in the ASD associated with pervasive vocal or motor stereotypies (Boyd, McDonough & Bodfish, 2012; DiGennaro Reed, Hirst & Hyman, 2012; Mulligan et al., 2014). The educational interventions based on *Functional Communication Training*, on the teaching of self-regulating skills and on the Differential Reinforcement strategies are sited in this grouping.

One of the first studies related to the capacity-based approach is that of Kennedy (1994), in which a 10-year-old student with ASD and multiple motor stereotypies was included in a training oriented to teaching the communication skills needed to obtain an object desired. The learning of the effective methods of request makes so marginal the recourse to the maladaptive behavior used to express the request (Bondy & Frost, 2002; Mirenda & Iacono, 2009; Boyd, McDonough & Bodfish, 2012).

Of similar interest is the study by Mancina et al. (2000), based on the development of self-monitoring and self-regulation skills. In the study, conducted on a 12-year-old student with ASD and severe vocal stereotypies, the participant was included in a training for to monitor, record and self-reinforce their behavior; the training was conducted by the teacher of the class in which the pupil was included. The development of the skills of self-monitoring had positive effects on self-regulation skills, and the vocal stereotypies were significantly decreased (percentage of reduction of stereotypy: 80.64%).

A study reported by all the main meta-analyzes is that of Lang et al. (2010), in which 4 students with ASD and massive motor and manipulative stereotypes, aged between 5-11 years, were submitted to the teaching of adequate playing skills. In this experimental design, the intervention phase was preceded by a phases of generic intervention for to verify the comparison on the reduction of stereotypies. While the alternative intervention did not have significant effects on their reduction, the teaching of appropriate playing skills resulted in a decrease in repetitive and manipulative behavior (percentage of reduction of stereotypy: 78, 39%).

Techniques of this order could present high inclusive opportunities for students with ASD. The possibility of teaching play skills by the support of the teacher or of the peers thorough the cooperative learning could form an integral part of the educational strategies for the decrease in repetitive behaviors. Also the *Differential Reinforcement of Other behaviors* (DRO) strategies have high levels of effectiveness in reducing stereotyped behavior (Boyd, McDonough & Bodfish, 2012; Mulligan et al., 2014). The Differential Reinforcement techniques are configured as non-aversive educational techniques, based on reinforcing behaviors alternatives to maladaptive ones. The reinforcement, represented by access to the activities or toys preferred by the student, is provided only when the stereotypies are not presents. During the episodes of maladaptive behavior, the reinforcement is never provided (Matson et al., 2012). DRO techniques have proven effective for the reduction of stereotyped behaviors of vocal and motor order.

A valid demonstration of their effectiveness can to be deduced from the study by Nuernberger et al. (2013), in which the goal of the educational intervention was represented by the reduction of the behavior of continuous manipulation of hair by a 19-year-old girl with ASD. The recursive differential reinforcement of behaviors different from those associated with stereotypy through the access to objects competitors with the maladaptive behavior, determined its almost total extinction (percentage of reduction of the stereotype: 98.8%).

A further demonstration of the effectiveness of DRO techniques comes from the Lanovaz & Argumedes study (2010), which involved a 3-year-old child with ASD and motor stereotyping of introducing objects into the mouth. The selective reinforcement of behaviors rather than the maladaptive one has led to a significant reduction (percentage reduction of the stereotype: 50.67%). If the use of the Differential Reinforcement techniques were suspended, a massive reappearance of the maladaptive behavior was registered (percentage of reduction of the stereotype: 9.94%).

Final considerations

The present review, although not exhaustive, could provide reflective opportunities on the involvement of the techniques derived directly from the ABA approach in the educational intervention programs for the students with ASD associated to stereotyped and repetitive behaviors of vocal and motor order. The massive presence of such behaviors in the behavioral profile of the student may represent a factor that can hinder both the processes of school inclusion (Murphy et al., 2009; Langen et al., 2011b).

The use of the techniques in the educational contexts of the Primary and Secondary School, through the regulation of access to toys or the specific interests of the student, in fact present clear inclusive opportunities. The techniques indicated should not therefore be considered only for reducing repetitive behavior, but also in the perspective of developing the functional communication skills. The development of communication and social skills, in turn, is a common goal for all models of educational intervention aimed at students with ASD.

The reference to techniques that present highest levels of effectiveness towards the maladaptive and stereotyped behaviors presents, in other words, inclusive opportunities that could be considered in the realization of each individualized educational intervention. The use of the techniques derived from the ABA approach, so, could represent a non-marginal component of the skills of the support teacher involved in the processes of Special Education oriented toward the reduction of the maladaptive behaviors.

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Sexuality and Sex Education in Autism

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Introduction

The clinical and scientific interest in sexuality, sexual behavior, and sexual education in autism is quite recent. The official discovery of the autistic syndrome dates back to the Second World War. It was not until 1981 that Asperger's syndrome was re-evaluated by Lorna Wing (1981), and not until the 1990s that it began to spread among clinical diagnoses. Autism was immediately considered a serious disorder in social interaction and interpersonal communication. With reference to autism, even the fourth edition of the DSM spoke of an absence of emotional reactions. Under these conditions, it is understandable that there has been a rather modest interest in sexuality in autism for several decades. More than anything else, sexual behavior in autism was considered a problem to be managed in cases where it was relatively dysfunctional and inadequate thus undermining the normal nature of the individual's interpersonal conduct based on the canons of conventional morality.

We must recognize that only psychoanalysis has always maintained an important focus on sexuality, even of autistic individuals. Indeed, starting from Freud, the place occupied by sexuality in psychoanalytic theory has produced the effect that sexuality, even in the psychotherapeutic treatment of autistic subjects, has maintained a prominent position in understanding the disorder and in exploring the psychic life and the internal world of people with autism.

Today it seems difficult to deny the fact that, without exception, all subjects with autism spectrum disorder (ASD) potentially experience sexual impulses. Many desire a sexual life and they have the right to live and express their own sexuality (Cabral Fernandes et al., 2016).

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In a certain way we are witnessing a contradiction that is manifested in the study and way of dealing with the question of sexuality in autism. The key concept of the new Inclusive Education model (e.g., Mitchell, 2015), which is taking shape internationally, whose key concepts expresses a focus on all the differences (Cottini, 2017). Moreover, it supports the importance of an environment that fits the needs of all individuals, starting with those with disabilities. In this light, disability is understood primarily in relation to the concept of those physical and even social obstacles that place limits and restrictions on individual functioning (Booth, Ainscow, 2011).

However, the sex education measures we make available for autism are placed in a perspective that we could otherwise define as conservative. What we try to teach as much as possible to individuals with ASD are those social rules that favor the integrity of the modesty barrier about sexuality. Alternatively, we should consider the subjects that break this barrier abnormal and susceptible owing to this of being excluded and placed on the margins of society. This occurs when the interest for the expression of an often problematic yet no less authentic sexuality is downplayed.

In developing this viewpoint throughout this chapter, we will see how it is fundamental to favor an intermediate, mediatory position. Moreover, social rules relating to sexuality must be taught to subjects with ASD, which has valuable beginning immediately and as soon as possible in the evolutionary arc, so that they can accept these rules and get used to adapting to them.

On the other hand, however, it is equally essential that the person with ASD can express his own sexuality, perhaps with some bizarre, but nevertheless rich aspects and the expression of a free, vital mind seeking to realize his own identity and personality.

1. Characteristics of sexuality in autistic mental functioning

As previously mentioned, the sexuality of subjects with ASD has been and still is largely denied and misunderstood on a social level (Byers et al., 2013). Moreover, it is like the sexuality of other disabled subjects, especially those with intellectual deficits. There are multiple reasons for this prejudice, but, firstly, in the sense of disgust and perturbing ambivalence that sexuality in disability arouses in the average individual. There is the right to express sexuality even in conditions of impairment and disability (Fratini, 2016). From the viewpoint of conventional morality, there is still a long way to go to fully accept a sexuality that is expressed in non-canonical conditions. Another example applies to the sexuality of homosexuals, but especially to elderly people, who, according to conventional morality, are thought now to be sexless and unable to abandon themselves to the uncanny pleasure of sexuality. A pleasure that in similar conditions is assumed to be perverse and therefore capable of inducing an automatic reaction of disgust.

Indeed, it is certainly true that sexuality poses formidable problems for understanding mental functioning in autism. A subject with ASD is in great difficulty when faced with any kind of social stimulation. A person with autism – by definition a form of disability in social interaction and communication, with a restricted and repetitive repertoire of interests – theoretically should not express a true erotic desire. People with ASD, at any level of functioning, reveal little interest in dealing with other people. They may not greet other people or look into their eyes. They often do not give the impression of recognizing others, and do not show any expression of interest and desire for interpersonal contact.

Yet sexuality is present in individuals with ASD. Not only do people with ASD undergo pubertal development, with all its physical, biological, and hormonal changes, but they also show the characteristics of sexual excitement: penile erection in males, vaginal and clitoral lubrication in females.

According to a restrictive view, one might be led to imagine that, in a subject with ASD, there is potential sexual excitement, in the absence of true erotic desire. Unlike sexual excitement, erotic desire presupposes affective investment in reality or fantasy of a real person, as someone other than oneself, culminating in the biologically determined orgasmic response (Kernberg, 1995). Autism's response would therefore be a sexuality that is not subject to sexual excitement. A split sexuality expressed in the spaces left free by the limitations of autistic pathology, where a subject with intermittent ASD has the possibility of leaving the withdrawal states typical of autistic mental functioning.

Let us recall that there is no mechanism in autism that is all or nothing (Barale & Ucelli, 2006). Autism places very serious limitations on social interaction and consequently on intellectual functioning, but these limitations are not always permanent. At certain times, the individual almost miraculously emerges from the autistic mental functioning and is able to show what are called "islands of capacity" in jargon. They are sometimes particular talents, whose root is still mysterious, yet which are the expression of a very particular and peculiar mental functioning.

Sexuality certainly has a place in the context of this functioning. Indeed, it is a sexuality strongly limited by the obstacles imposed by the autistic pathology. Subjects with ASD have difficulty with theory of mind, empathizing, and grasping other people's points of view (e.g., Stokes & Kaur, 2005), indispensable for having a sexual interest, but especially for falling and being in love.

While puberty in autism develops regularly, the same cannot be said for adolescence as a social and psychosexual phenomenon. The characteristics of normal adolescence, with the working trough of grief for the end of childhood, separation from parents, and access to the "social container" provided by the peer group almost always preclude subjects with ASD.

In fact, autism is characterized by a peculiar social isolation that is, nevertheless, sought by the autistic subject, preventing those relationships of comparison to the same age group that are an important source of social experimentation for sexual purposes and typical of normal adolescents.

Despite these limitations, clinical observation has shown that individuals with ASD do have a sexual life; they experience sexual impulses. However, the most recent studies also demonstrate something more: a declared interest on the part of autistic adolescents and young people towards a couple's sexual relations and romantic love (Strunz et al., 2017).

In fact, the issue of sexuality in autism still faces many prejudices today. One very important prejudice is that these individuals would be incapable of experiencing real intimacy in a loving and sentimental dyadic relationship with another person. The lack of empathy and of theory of mind would block the possibility of any intimate emotional relationship (Stokes & Kaur, 2005).

Another prejudice is that the sexuality of these subjects is unequivocally perverse and thus to be discouraged rather than encouraged. In this regard, the fact that there is a higher percentage of homosexuals and bisexuals in subjects with ASD than in the normal population is controversial (Turner, Briken & Schöttle, 2017). According to some research, the population of people with ASD has a greater percentage of individuals that are homosexual and bisexual in addition to those claiming to have various forms of paraphilia. The percentages are however low and limited to a range that does not appear so different from those in the neurotypical population.

The presence of homosexuality in autism can be explained as linked to the fact that, in some cases, the sexuality of subjects with ASD, in some ways, would be immature, blocked at a perverse-polymorphic stage like the one theorized by Freud (1905). More than a question of true homosexuality, it would be one of a sexuality struggling to be emancipated towards the adult stage, owing to the considerable obstacles imposed by the mechanisms of autistic mental functioning as a limit to the development of a harmonious and mature personality.

2. Sexual education in autism

As social awareness of sexuality in autism has grown, the concept of a need for sexual education for people with ASD has been increasingly articulated. This is important for both high-functioning and lower-functioning autistics. Contrary to prejudices and to what might be mistakenly thought, people with ASD not only have a sexuality but also a capacity to learn social and sexual rules, if they only have the opportunity to meet people who have the patience to teach them.

Sexual education is made necessary because the neurotypical child and adolescent's intuition and spontaneous learning in many cases must instead be taught to and systematically learned by the subject with ASD.

Sexuality education also in autism is therefore something that can be taught, even if it is appropriate here to clarify something. Sex education cannot be resolved by the person with ASD merely by attending a training course. It must necessarily begin much earlier, essentially beginning in childhood (Dagna & Margaria, 2016), and the parents' attitude and disposition plays a fundamental role in this.

In this regard, it should be noted that many parents are still unprepared to face a serious discussion on the sexuality of their children with ASD. They are somewhat reluctant and incompetent in this area (Ballan, 2012). The parents' incompetence is certainly understandable in the face of this demanding task, but it also covers the fundamental issue regarding the sense of guilt that the parents inevitably have towards a child with ASD.

This sense of guilt is a defense against the psychic pain that the parents feel towards the disability affecting their autistic child. From this, an attitude develops that infantilizes the child along with a belief that, with the passing years, the child increasingly suffers. Indeed, the recognition of sexuality is closely linked to an idea of growth and change. Many parents still prefer to think that a condition in which their child is strictly dependent on them is preferable to one in which, to the extent possible, the child gradually becomes autonomous and independent. The parents' overprotectiveness of a child with ASD is always a problem to take into consideration and one that can intensify their own child's social disadvantage.

It is necessary to pause on the overall theme of the complexity of sexual education for an individual with ASD. As mentioned, the complexity is such that the parents' continued commitment from the early stages of the child's development should be required.

Moreover, sex education in autism should consider various aspects and seriously address numerous issues.

One aspect entails the difficulty of subjects with ASD to distinguish between public and private (Ballan, 2012; Stokes, Newton & Kaur, 2007). Individuals with ASD very often find it difficult to distinguish between public behavior and private behavior and between parts of their own body and those of other people, those parts that can be exhibited and touched and those that must remain covered or protected in public behavior. A person with ASD may discover or touch their own genitals in public, or likewise touch the intimate parts of other people. Individuals with ASD also may not be able to distinguish between kisses and affection towards people they know and with whom they have an intimate relationship from contact with strangers with whom the modesty barrier cannot be broken (Realmuto & Ruble, 1999).

The "social blindness" typical of autism means that these behaviors, which are not perceived and understood spontaneously, must be specifically learned by individuals with ASD. The risk in this case can be to the point of accusing an autistic person of obscene acts in public places (Dagna & Margaria, 2016).

There are two other essential risks for people with ASD that need to be addressed and for which sex education is needed. For females, there is the risk of unwanted pregnancies. Sex education from this point of view must cover the risk of pregnancy and an explanation to the girl on the importance of using contraceptives and condoms as a way to deal with this risk.

The second, very important risk is sexual abuse. People with ASD, especially those at a low-functioning level, may not be able to cope with sexual abuse (Sevlever et al., 2013). Not only may they not be able to defend themselves from the abuser, they may also not be able to describe and report the abuse immediately. Due to their candor, naivety, and social incompetence, people with ASD can easily be chosen by unscrupulous individuals who can commit sexual abuse.

From this point of view, to combat the risk of sexual abuse, it should be noted that abusers are very often people who are part of the immediate circle of those spending time and interacting socially with the person with ASD on a daily basis (Reynolds, 2013). Careful monitoring of these people's conduct can be one way to reduce the risk factor associated with sexual abuse.

A third risk is linked to sexually transmitted diseases. Again, in this case, male and female subjects with ASD should be informed about the danger of contracting a disease and be encouraged to use condoms.

Another essential aspect of sex education is related to personal hygiene. Parents should teach their children with ASD both to take care of the hygiene of their private parts and to be aware of a number of other important aspects. Reynolds (2013) has listed some important elements on this point that take the personal hygiene of adolescents with ASD into consideration. Some examples are the male's ability to learn how to shave facial hair and to urinate in the correct standing position and a female's to learn how to remove body hair and to use sanitary pads during the menstrual cycle.

Parents of children with ASD should explain the fact that a male's voice goes through a change and that parts of the body, e.g., breasts in females, undergo a transformation.

An additional element in a relationship with one's body is to learn privacy and secrecy. Many parents are reluctant to teach their child with ASD to sleep alone. Instead, they should do their best to teach the child to sleep in their own room and to try to make them understand that this can be a private space where the child can pursue his own intimacy and secrecy.

With the advent of puberty, this secrecy essentially concerns the discovery of secretions from one's own body (Novelletto, 2009). Since the individual with ASD cannot learn these concepts from his peer group as he tends to be excluded, it is up to the parents to teach these facts to their child. Privacy is a central concept of adolescence and adulthood that could and should be appropriately taught to a person with ASD.

Another aspect of sexual education that should be taught to subjects with ASD concerns inhibiting exhibitionist behavior, which may include touching oneself or even masturbation in public, stripping, and an inability to understand other people's need for privacy. From this point of view, the issue also answers the fundamental question of what is and is not appropriate in a given situation. This concept, which neurotypical people understand spontaneously, can be difficult for a person with ASD to acquire and must be taught and learned.

We enter the world of friendships at the same age and into sentimental relationships with our contemporaries. Naturally, this can mean coming to terms with a world that imposes powerful frustrations on people with ASD. The complicated relationship of ambivalence created in sentimental and intimate relationships with people of the opposite sex, similarly to same sex relationships, can cause misunderstandings and intense frustration on the part of adolescents with ASD. They must learn to understand the concept of rejection by the other and also learn how to tolerate and manage it. This can be the source and cause of great psychic pain.

Moreover, like all emotionally immature people, people with ASD may tend to idealize greatly the objects of their sexual and loving desire. All this exposes them to greater disappointment when they experience rejection.

If parents play an essential role in also the sexual education of their ASD child, this does not mean that clinical specialists, educationalists, and researchers cannot develop a good sex education program.

Gradually, valid sex education programs for people with high- and low-functioning ASD are springing up. Some of these programs have also been validated and have a high degree of empirical confirmation (e.g., Visser et al., 2017).

One of these programs is Tackling Teenage Training, whose acronym is TTT (Boudesteijn et al., 2011). This is a program developed expressly for adolescents with high-functioning ASD. The basic assumption driving the concept developed by the program is to regard sexual functioning as a complex construct that integrates diverse aspects. It considers not only the sexual act and knowledge of sexual apparati, in addition to intimate hygiene, knowledge of one's own changing body that extends to facts and Self-awareness, together with the resolve to have peer-group socialization experiences, up to intimacy in sexual relations and romantic love (Dekker et al., 2015).

Sex education programs conducted by educational specialists should now be considered. Attending a course for only a few hours can be used to convey some ideas to individuals with ASD about the functioning of their body and of sexual relations. However, for individuals with ASD to fully learn to manage the potential of their sexual functioning, it can naturally take a long time. As mentioned, it is the parents' as well as the specialists' input that can make an important contribution in this long fundamental process.

They can develop special settings in which learning the facts and skills of sexuality can be carried out agreeably in a climate where adolescents or even adults with ASD can experiment in the context of pleasant relations.

To do this, a specific setting should be organized: a room in which to meet regularly and to hold regular, i.e., weekly, meetings and not for too short a period of time. The lessons could include using social stories and simulating situations in which intimate contact occurs between the participants.

In fact, the last chapter in the sexual education of individuals with ASD fades in the normal social interaction between people, who meet, get to know each other, and have an intimate affective sexual relationship, either heterosexual or even homosexual.

As Moscone (2016) writes in his introduction to Sarah Attwood's sex-education manual for subjects with Asperger's syndrome (Attwood, 2008, p. 10):

> Any sex education program must therefore enable people to make informed, conscious choices and to act responsibly towards themselves and their partners; have an awareness and knowledge of the human body; be able to express feelings and needs; develop one's own sexual identity; acquire adequate information on physical health, hygiene, and the prevention of sexually transmitted diseases; have the necessary skills to manage all aspects of sexuality and relationships; establish equal relationships in which there is mutual understanding and respect for shared needs and boundaries; be able to talk about sexuality, emotions, and relationships; and have the right language available.

From this point of view, the first, groundbreaking research is emerging that highlights the need for romantic relationships on the part of high-functioning subjects with ASD (Strunz et al., 2016). By debunking the prejudice those individuals with ASD lack emotional reactions, such research has increasingly shed light on the fact that many people with ASD want a romantic relationship and are willing to engage in such relationships. This shows that particularly women with ASD, more than men, have already engaged in such relationships to a greater extent than we might think based on prejudice (Strunz et al., 2016).

Many people with ASD are involved in a relationship, either with other autistic partners or with neurotypical people. However, one aspect that still seems to be covered by negation mechanisms and denial is the experience of coitus. There are many discussions in sexual education manuals on people with ASD preparing for sexual intercourse. Nevertheless, actual experiencing the sexual act still seems to be hidden by a wall of reluctance in field research. Do people with ASD eventually have sexual relations? Moreover, if so, are they gratifying? It is this question that we increasingly deserve to have an answer from future research.

3. Sexuality in autism and psychotherapy

Psychotherapy is a complex, highly specialized area, whose vast body of literature on the treatment of autistic people has existed for many decades. A discussion on autistic psychotherapy is largely outside the scope of this paper. Suffice it to briefly mention the fact that it is significantly linked to the contribution of psychoanalysis, which has received much criticism for its psychogenic etiopathogenic considerations of autism's causes and origins, and which today still tends to be viewed with suspicion because of its contrary approach to evidence-based research.

However, a careful analysis of the clinical contributions of psychoanalytic psychotherapy of autistic children, adolescents, and adults displays a wealth of ideas and contributions, especially from the point of view of people with ASD exploring from within their subjective experiences.

We may argue that good psychotherapy can be a valuable added contribution to the treatment and overall management of people with high- and low-functioning ASD. Psychotherapy works primarily by improving the capacity for symbolization and mentalization (Fonagy & Target, 2001). This can promote the personality's harmonious growth. The elements and channels along which psychotherapy acts are therefore linked also to the management and reduction of aggression and problem behaviors, a greater Self-awareness and consciousness, a better relationship with one's own sexual body, working through mourning for the psychic pain of one's personal history, and a more detached, differentiated view of oneself in relation to one's parents.

In short, psychotherapy can foster greater autonomy for people with ASD and thus also prepare them for the experience of sexual love and of encountering a partner in a rewarding and fruitful loving relationship.

Conclusions

Concluding this chapter, we can assert that this recognition of sexuality and sexual needs in autism indicates how much progress has been made since the first research on the syndrome, and how much still is to be done in terms of an ever more complete emancipation of subjects with ASD, starting in adolescence and then gradually increasing into adulthood.

We began this chapter by stating critically how it is a challenge to the concept of inclusion subjects with ASD to fully recognize their sexuality. In fact, it would be a mistake to support as a correct education of the person with ASD passes through in all respects following those social conventions that our society of adults and adolescents, even rather inflexibly, demands. One limitation of such neo-behavioral approaches as the ABA method (Lovaas, 1981) is perhaps over insisting on an educational and rehabilitative treatment of the person with ASD in faithful function of his social adaptation.

We know that there remains a bit of madness and oddness at all functioning levels of autism. We advocate for these aspects to also be accepted and valued for purposes of social inclusion and the psycho-affective well-being of people with ASD. Most people with ASD from autism cannot be cured. However, this does not mean that they cannot learn many things about life, human relationships, and sexuality in particular. Autistic people are clearly entitled to fall in love and experience their sexuality, which is also owing to their support experiences.

The sex education model we have in mind is not limited to imparting knowledge to subjects with ASD. It must aim for something more and not merely for the individual to become familiar with his own sexuality, but also to prepare and encourage sexual encounters between people with or without ASD.

Undoubtedly, the frontier of the future is towards the ever increasing social inclusion of autistic people. This means setting up, creating, and developing opportunities in which people with ASD, males and females, may meet to find and experience sex that consider the moment of exchange and sexual intercourse.

Furthermore, what is the use of learning an extensive rulebook on sexuality, if it is not directed at an experience of sexual love? At the same time, we cannot expect that autistic people's experience of sexuality, like life and human relations in general, conforms fully to the rules that the neurotypical community has adopted to experience normal social relationships.

The ideal would be if people with ASD could experience romantic relationships with neurotypical people, which would gradually help them to better understand themselves and to take important steps towards autonomy, alleviating the pressure and constant anxiety of being different from the others and having many problems.

However, even the experience of a relationship between partners, both with ASD, can be important, and to foster and encourage the current situation. Two people with ASD having a relationship can accept each other's problems more easily. They may feel less performance anxiety, fear of abandonment, and anxiety about being judged "strange" because of their autistic traits and behaviors.

Lawson (2005) pointed out an important feature of autistic behavior in a loving relationship: monotropism. Individuals with ASD are less able to tolerate ambivalence in a romance. They need to have one experience at a time during the day and may suffer mental overload when the relationship becomes more complex and other contradictory elements tend to come into play.

However, people with ASD fall in love, experience sexual impulses, albeit in unusual ways at times. We hope that they can increasingly have the experience of a gratifying emotional and sexual relationship.

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The Autistic Spectrum Disorder and the Quality of Life. Researches, Instruments, Results

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Introduction

The Autistic Spectrum Disorder (ASD) is currently one of the most common developmental disorders, with an incidence of 1 to 59 children, affecting five times more boys than girls (information available online at https://www.psychiatry.org/patients-families/autism/what-is-autism-spectrum-disorder), whose symptoms appear early in childhood (12-18 months), with symptoms most commonly seen around the age of 2-3 years.

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM 5), developed by the American Psychiatric Association, the autistic spectrum disorder is characterized by: socio-emotional deficiencies (regarding involvement in conversations, sharing emotions and feelings, initiation or response to social interaction); deficiencies in non-verbal communication (visual contact, mimic-gestural language, lack of facial expressions; deficiencies in developing, maintaining and understanding relationships (difficulties in playing with other children or making friends, lack of interest in other children). To these deficiencies are added repetitive, stereotypical behaviors, fixations, inflexibility regarding the deviation from the routine (APA, 2013: 50-51).

Quality of life is a concept used for the first time in the United States of America after World War II to describe the effect that well-being (defined by the possession of houses, cars and other consumer goods) has on people's lives, term later on extended on other areas, such as education or health (Carr, Thompson & Kirwan, 1996: 275; Kumar, 2018: 30). In the socio-medical literature, the term has often been considered synonymous with life satisfaction, self-esteem, well-being, happiness, health, value of life, meaning of life (Kumar, 2018: 30).

Quality of life is a multidimensional, dynamic concept that can undergo changes throughout the lives of individuals. From the perspective of the World Health Organization, the quality of life is defined as:

> … an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, and standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment (apud Carr, Higginson & Robinson, 2003).

By the quality of life we can understand the degree of satisfaction that a person has towards the dimensions of his life, compared to what constitutes, for that person, the ideal, in close relation with the cultural and value system to which the individual relates. Any change in living conditions (health, occupation, freedom of action or expression) can induce a change in the image regarding the quality of life (Kumar, 2018: 30-31).

Robert Schalock states (Schalock, 2000), that the origins of the concept of quality of life lie in the actions undertaken in the field of services, education and health for people with mental disabilities, being widely used in medicine (apud Plimley, 2007: 205). The same author (Schalock, 1996, apud Plimley, 2007: 207) considers that there are eight dimensions of the concept, namely: physical well-being, material well-being, interpersonal relations, social inclusion, personal development, self-determination, emotional well-being and rights.

From a sociological perspective, the research of the quality of life follows the living conditions of the individuals and their perceptions on these conditions (Precupețu, Preoteasa & Pop, 2007: 197). According to the ICCV (ICCV, 2017),

> quality of life is the value for man of his life; how good or bad is the life he lives, both as a whole, and on his particular components: health status, family, profession and work place, available financial resources, assets he owns, leisure time, social environment, friends and colleagues, the society in which he lives. Quality of life represents the global, synthetic quality of all conditions and spheres of which life is composed; the degree to which life produces satisfaction.

Quality of life research is institutionalized in 1995, with the establishment of the International Society for Quality of Life Studies (Veenhoven, 2007: 54). In Romania, quality of life is a favorite area for the research carried out by the Institute for Quality of Life Research (ICCV); quality of life indicators have been introduced since the 70s, both objective (income, consumption, living conditions, environmental quality) and subjective (indicators of life satisfaction, indicators of perceived quality of life in its different spheres) (ICCV, 2017).

In the studies undertaken on the quality of life of people with ASD, health issues were mainly addressed, from a socio-medical point of view the quality of life being related to terms such as: satisfaction, self-esteem, happiness, well-being, wealth, value, adaptation (Carr, Thompson & Kirwan, 1996: 275).

The present approach aims to analyze, without pretending to be exhaustive, the existing literature to date, in order to create an overview on the research undertaken on the quality of life of people with ASD (especially children), on the methodology used and of the results of these researches. That it cannot be an exhaustive research is evident from the reading of a previous study (Ikeda, Hinckson & Krägeloh, 2013), which identified in online databases (MEDLINE, CINAHL Plus, SPORTDiscus, EBSCO Health Database, PsycINFO and ProQuest Health and Medicine), for the period 2000-2013, a total of 1165 titles of articles written in English and German, available in full text, analyzing the quality of life of children and young people with TSA. However, categorically, the published researches and studies are much more numerous.

Studies on researches on the quality of life of people with ASD can be classified into two categories: studies that directly investigate the quality of life of the person diagnosed with ASD (Kuhlthau et al., 2010; Egilson et al., 2017) and studies that track the quality of life of families with children with ASD (Cashin, 2004; Church, 2006; Kheir et al., 2012; Hoefman et al., 2014), the impact that a child's diagnosis has on caregivers. In this second category, a sub-category can be identified, which receives special attention from researchers, namely the quality of life of mothers with children with ASD (Boyd, 2002; Salehi et al., 2017). Another observation that emerges from the literature analysis is the tendency to analyze the quality of life in the comparative register (children with ASD - neurotypical children), to compare the scores and results recorded by the two categories and to conclude accordingly (Boyd, 2002; Church, 2006; Egilson et al., 2017).

1. Researches on the quality of life of children with ASD

Communication deficiencies, non-verbalism or difficulties in initiating and involving children with ASD in social interactions are major impediments in conducting direct studies on this category of children. For this reason, the direct investigation of the quality of life of children with ASD is carried out in most cases by analyzing the parents' point of view. Some exceptions (Egilson et al., 2017) may be encountered in the case of verbal children with highly functional autism, who have the ability to understand and respond and thus to provide their own perspective on their life.

Ikeda, Hinckson and Krägeloh (2013) consider that, since the perception of quality of life is subjective and personal, it is preferable to obtain direct answers, and not from the proximity of the child, although, as we have already mentioned, this fact is most often impossible.

A special category is that of young people with highly functional ASD or Asperger's syndrome, whose personal image on their quality of life has been the subject of several studies. A first study (Jennes-Coussens, Magill-Evans & Konin, 2006, after Burgess & Turkstra, 2010: 476-477) compared the values recorded by 12 youths with ASD with those of 13 neurotypical youths, using the WHOQOL-BREF questionnaire, finding overall lower values registered by young people with ASD, with significant differences in physical health and social relations. Renty & Roeyers (2006) (after Burgess, Turkstra, 2010: 477) used the Quality of Life Questionnaire (QoL.Q) to investigate the quality of life of a sample of 58 youths with ASD. QoL.Q is a standardized tool, comprising 40 items classified in four areas: satisfaction, well-being, social belonging and control. The very interesting conclusions of the study showed that for adults with ASD the severity of the disorder or the coefficient of intelligence are not capable of affecting their quality of life; instead it is observed that the asymmetry of perceptions between the desired social support and the one received negatively affects the quality of life of these subjects.

Adolescents with high-functioning autism/Asperger's syndrome have been the subject of a study in the United States, on a group of 15 young people (reported to a control group with an equivalent number of subjects) (Burgess & Turkstra, 2010). The instrument used was the Quality of Communication Life Scale (QoCL), a questionnaire with 18 items, of which 17 specific statements, the 18th being a summative assessment of the quality of life. For each of the 18 statements the subjects must give grades from 1 to 5 (Burgess & Turkstra, 2010: 479).

The statistical data showed lower values for the subjects diagnosed with ASD, compared with the neurotypical ones, also lower scores for the answers offered by parents, compared with those of the children. Surprisingly, no significant differences are found between adolescents with ASD and neurotypical ones regarding the values recorded in the summative statement "In general the quality of my life is good", values that in both cases were high, compared to the scores obtained by the young people with ASD on the other 17 statements. The possible explanations identified by the researchers lie either in the fact that young people tend to give positive answers to questions that concern abstract concepts, rather than to those that involve concrete situations, or that the overall quality of life is not negatively influenced by the difficulties with which young people with ASD face (Burgess & Turkstra, 2010: 482).

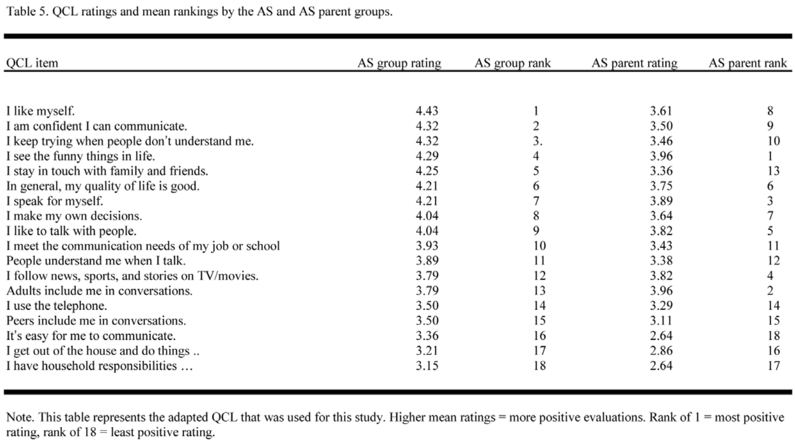


Table 5. QCL ratings and mean rankings by the AS and AS parent groups.

QCL item	AS group rating	AS group rank	AS parent rating	AS parent rank
I like myself.	4.43	1	3.61	8
I am confident I can communicate.	4.32	2	3.50	9
I keep trying when people don't understand me.	4.32	3.	3.46	10
I see the funny things in life.	4.29	4	3.96	1
I stay in touch with family and friends.	4.25	5	3.36	13
In general, my quality of life is good.	4.21	6	3.75	6
I speak for myself.	4.21	7	3.89	3
I make my own decisions.	4.04	8	3.64	7
I like to talk with people.	4.04	9	3.82	5
I meet the communication needs of my job or school	3.93	10	3.43	11
People understand me when I talk.	3.89	11	3.38	12
I follow news, sports, and stories on TV/movies.	3.79	12	3.82	4
Adults include me in conversations.	3.79	13	3.96	2
I use the telephone.	3.50	14	3.29	14
Peers include me in conversations.	3.50	15	3.11	15
It's easy for me to communicate.	3.36	16	2.64	18
I get out of the house and do things ..	3.21	17	2.86	16
I have household responsibilities …	3.15	18	2.64	17

Note. This table represents the adapted QCL that was used for this study. Higher mean ratings = more positive evaluations. Rank of 1 = most positive rating, rank of 18 = least positive rating.

Figure 1 (after Burgess &Turkstra, 2010: 481)

Another study we will refer to was conducted in 2010 on a sample of 286 children from 15 centers in the United States and Canada (Kuhlthau et al., 2010). It is the first study to track the quality of life of children with ASD in the United States and Canada (Kuhlthau et al., 2010: 728). The study focused exclusively on the quality of life defined from a socio-medical point of view, comparing the values recorded by children with ASD with the values recorded by neurotypical, healthy children, but also children suffering from other chronic conditions, from official data, statistically recorded. Information on the quality of life of children with ASD was collected from parents through a standardized questionnaire. The Pediatric Quality of Life Inventory - PedsQL is a 23-item questionnaire, applicable to children aged 2-18 years, which assesses four dimensions of the quality of life, namely: physical, emotional, social and school performance (Kuhlthau et al., 2010: 723). It is one of the most used tools used to investigate the quality of life of children with TSA (according to Ikeda, Hinckson & Krägeloh: 2013). Statistical analyzes revealed significant differences between the categories of children, with values for total net inferior in the case of children with ASD. For two dimensions, namely physical condition and school performance, the scores were somewhat comparative between children with ASD and those with chronic conditions (Kuhlthau et al., 2010: 726). A very important variable that significantly changed the responses provided by parents was the age of the child, the older the child was, the lower the recorded values, the possible explanations being the cumulative stress of the parents, the evolution or the lack of progress of the child in time (Kuhlthau et al., 2010: 728).

In Iceland, a study was conducted on 96 children with ASDTSA, whose values were compared with those of a group of 211 neurotypical children. Respondents were mostly mothers (89.6% for children with ASD and 86.3% for neurotypical children) (Egilson et al., 2017: 134). The tool used in the research was KIDSCREEN-27, a standardized questionnaire, which emphasizes not only the capabilities of the child (as in the case of PedsQL), but also the subjective side, what the child feels, an aspect considered relevant by the researchers in order to outline a most suggestive image of the quality of life of these children (Egilson et al., 2017: 134). The research revealed statistically significant differences between the two categories of children, with low values recorded by children with ASD in indicators such as: social support, physical health, support from the elderly (Egilson et al., 2017: 136). What is extremely interesting and remarkable about this study is that it compared four perspectives, sometimes distinct, sometimes complementary, namely the parents' perspective (children with ASD and neurotypical children), and the perspective of children (with highly functional and neurotypical), as can be seen from Figure 2.

As can be seen from the graph, except for autonomy and relationships with parents, where both children with ASD and their parents recorded similar values, the means of responses to the other four dimensions recorded significant differences, the children having higher values, thus a better image than their parents (Egilson et al., 2017: 138). Interesting is the difference in perception in the case of neurotypical children and their parents, again the values recorded in the answers offered by children being higher.

Another very important finding that emerges from the analysis of the statistical data is the fact that, despite all the difficulties and problems, especially related to physical health (where the values recorded are the lowest), the lack of social support, the lack of friends or the

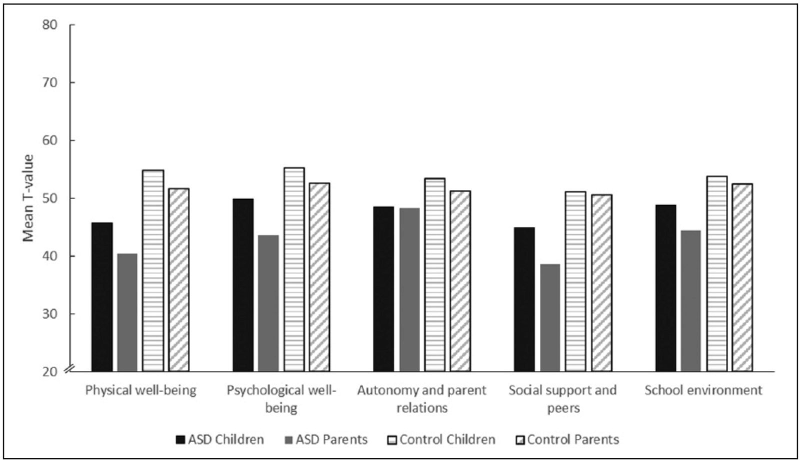


Figure 2 (after Egilson et al., 2017: 136, fig. 1)

difficult relationship with those of the same age, the highest values were recorded by children with ASD in the emotional health chapter.

In 2017, a report was published on the quality of life of children with TSA in Spain, following a research undertaken on a number of 1060 young people, of which 64.2% boys, aged between 4 and 21 years (Arias et al., 2017). In order to measure the quality of their life, from the perspective of the eight areas defined by R. Schalock, a 96-item questionnaire was designed to be completed by those close to the child (family, teachers, therapists). Each of the 8 domains are assigned 12 questions, whose answers are recorded in the form of a scale with four answer variants (never, sometimes, often, always), scored from 1 to 4. The total score is directly proportional to the quality of life (the higher the score, the higher the quality of life is considered). In conducting the research, the authors started from the hypothesis that not always the quality of life is affected by the diagnosis, but by other factors, such as gender, severity of intellectual disability or the services they benefit, hypothesis that is confirmed by the lower values recorded in the questionnaires regarding for girls and those with severe intellectual disabilities.

The latest study (Kumar, 2018) was conducted in India, on a sample of 60 people (30 parents with children diagnosed with ASD and 30 parents with neurotypical children). Standardized tools were used in the research, such as: the General Health Questionnaire (GHQ-28), a 28-item instrument developed in 1978, used to investigate the psychological effects that a child's diagnosis has on his parents; WHOQOL-BREF (the World Health Organization Quality of Life), made in 1998, contains 26 items and has been used to measure parents' perceptions of their lives in relation to their standards, goals, expectations and concerns; the Family Interview Schedule comprises 14 items, being used to measure the degree to which parents of children with ASD experience stigma (difficulties with neighbors, shame, guilt, depression) (Kumar, 2018: 31-32). Following the application of GHQ-28, it was observed that the parents of children with ASD suffer from psychological disorders significantly higher than the parents of the neurotypical children; significant differences between the two categories of parents were also observed after applying WHOQOL-BREF, on the social relations indicator. Following the application of the Family Interview Schedule, it was found that the diagnosis of the child does not have a negative impact on the quality of life of the parents, but the higher the age of the child, the higher the scores registered by the parents regarding the stigma (Kumar, 2018: 33).

2. Researches on the quality of life of families of children with ASD

All the studies undertaken so far have been based on the hypothesis that the families of children diagnosed with autism have a lower quality of life than those of the families of the neurotypical children, facing many shortcomings (financial, including a high level of stress, anxiety and other medical problems) and benefiting from insufficient social support, the family, and especially the core family (mother-father), is the one who fully takes care of the autistic child, including the financial effort needed to recover (Church, 2006; Boyd, 2002).

Families with children with autism face numerous problems: anger/disruptive behaviors; obsessions, broad or narrow interests; withdrawal or depression; lack of motivation; weak autonomy and organizational skills; strange behaviors in communities or legal issues (Gaus, 2010). By becoming almost totally involved in the care and recovery of the child, parents often give up themselves, limiting all other activities, facing social isolation, partly assumed, partly caused by the child's failure to be accepted in some environments (Cashin, 2004; Perumal et al., 2014: 791). In many situations, the diagnosis of the child is not only a challenge, but even a burden for families, forced to change their entire way of life (Kheir et al., 2012: 2).

In some studies, the analysis of statistical data revealed a very interesting conclusion, namely that sometimes families of children with autism reach a level of adaptation and resilience that allows them to record quality of life values comparable to those of families of neurotypical children (Church, 2006).

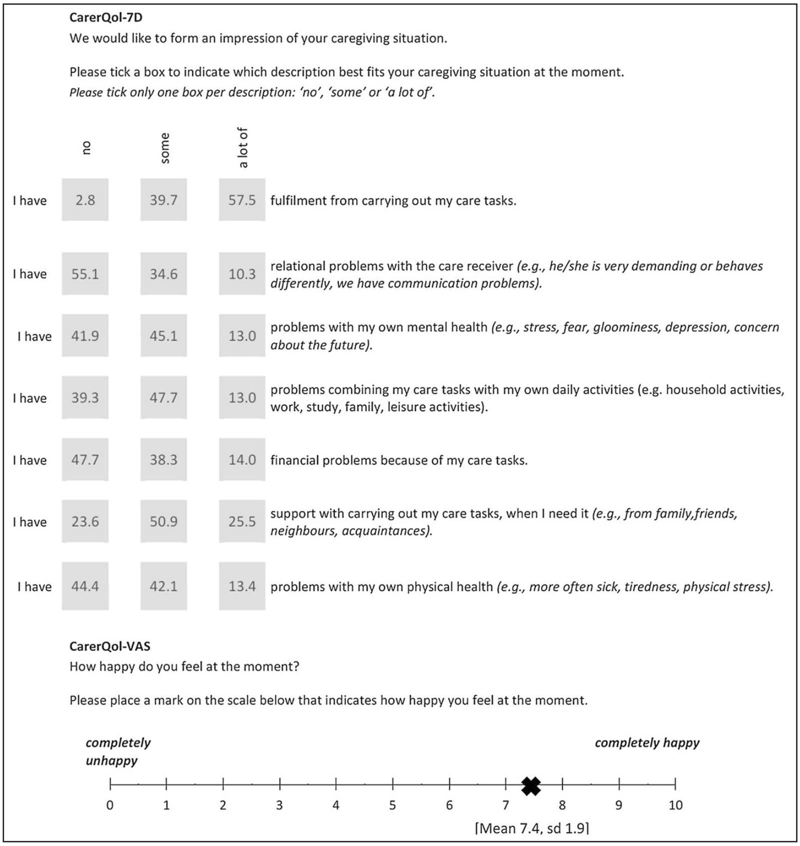
A research conducted in Qatar (the first of its kind here), on a number of 98 subjects, of which 56 parents of children with ASD and 42 parents of neurotypical children (Kheir et al., 2012), revealed that there are no statistical differences significant in terms of quality of life between the two categories of parents, but parents of children with ASD showed significant differences in their health, considered increasingly precarious (Kheir et al., 2012: 1). The averages recorded in the mental health chapter were smaller than those recorded in the physical health, although no significant statistical differences were observed between the two. An interesting finding of the study is that 57% of children with ASD are educated in special schools, those who are not, wanting to be educated in special schools (Kheir et al., 2012: 3). The tool used to investigate the quality of life was the Standard Recall Short Form Health Survey 36 (SF-36 v2), again a standardized questionnaire, made from the medical perspective of the quality of life, which follows eight dimensions: physiological, social, limiting activity as a result of health problems, limiting activity due to emotional problems, mental health, vitality, pain in the body, general health (Kheir et al., 2012: 3).

The quality of life of families of children with autism in India was investigated on a sample of 180 people (60 parents of children with ASD, 60 parents of healthy children and 60 parents of children with physical disabilities) (Perumal et al., 2014: 792). The research was therefore quantitative, the instrument used being WHOQOL-BREF. Statistical data showed a significantly lower quality of life for parents of children with ASD. Significant differences and lower values were observed for parents of children with autism regarding their health, negatively impacted by daily trips to therapies, long waiting periods, disturbed life rhythm, high stress level (Perumal et al., 2014v 794-795). The same situation was also observed regarding the social relations of the parents of children with autism, having to face the multiple challenges, from the ones of an emotional nature (deprivation, in many cases, of the children gestures of affection, due to their incapacity for expressing emotions), rejection by others (in India for the elders autism is a shame and a taboo subject), stigma, lack of support from the partner. From the point of view of the financial resources and of the feeling of security, again, the values registered by the parents of children with autism were statistically significantly reduced (Perumal et al., 2014: 795).

Some studies aim to correlate the quality of life of parents of children with autism with other factors, such as stress (McStay et al., 2013; McStay, Trembath & Dissanayake, 2014). This is the case of a study conducted on a sample of 196 parents from Australia, having children diagnosed with ASD aged 3-16 years (McStay, Trembath & Dissanayake, 2014). The level of stress recorded by them was statistically higher than for other categories of parents. It is noted that there are mechanisms of adaptation of parents and restructuring within the family, to ensure resilience and to cope with the situation.

A similar research was previously conducted in the Netherlands on a sample of 150 parents with children diagnosed with TSA, compared with a group of 54 parents with neurotypical children (McStay et al., 2013). The study, appreciated by the authors as the first of its kind, followed the effects (the level of parenting stress) that the diagnosis and implicitly the characteristics of the child have on the parents. The research, which used the PedsQL questionnaire, and to determine the parenting stress level the Parenting Stress Index, revealed that there are statistically significant differences between parents of children with ASD and neurotypical ones regarding the level of stress felt, the values of parents of children with ASD being higher. The age, severity of the diagnosis, the communication skills of the child did not have a significant impact, statistically highlighted, on the stress level felt by parents. Regarding the disruptive behaviors of children with ASD, hyperactivity is a factor that negatively impacts the level of stress felt by parents, as a result of which such behavior can lead to social unacceptability (McStay et al., 2013: 6-7).

Hoefman et al. (2014, 1934) drew attention to the fact that most of the research undertaken up to that time has followed the effects that the child's diagnosis has on parents, especially regarding their physical or mental health (stress, anxiety, depression), neglecting other major consequences, such as those of economic nature (costs, indebtedness, unemployment). The research they are carrying out is likely to explore all areas that have a potential impact on the quality of life of parents of children with ASD, which is why the instrument used is the Care-Related Quality of Life Instrument (CarerQol), another standardized and validated tool, which measures seven dimensions, two positive and five negative, of the impact that the child's diagnosis has on his parents.



CarerQol-7D

We would like to form an impression of your caregiving situation.

Please tick a box to indicate which description best fits your caregiving situation at the moment.

Please tick only one box per description: 'no', 'some' or 'a lot of'.

	no	some	a lot of	
I have	2.8	39.7	57.5	fulfilment from carrying out my care tasks.
I have	55.1	34.6	10.3	relational problems with the care receiver *(e.g., he/she is very demanding or behaves differently, we have communication problems).*
I have	41.9	45.1	13.0	problems with my own mental health *(e.g., stress, fear, gloominess, depression, concern about the future).*
I have	39.3	47.7	13.0	problems combining my care tasks with my own daily activities (e.g. household activities, work, study, family, leisure activities).
I have	47.7	38.3	14.0	financial problems because of my care tasks.
I have	23.6	50.9	25.5	support with carrying out my care tasks, when I need it *(e.g., from family,friends, neighbours, acquaintances).*
I have	44.4	42.1	13.4	problems with my own physical health *(e.g., more often sick, tiredness, physical stress).*

CarerQol-VAS

How happy do you feel at the moment?

Please place a mark on the scale below that indicates how happy you feel at the moment.

[Mean 7.4, sd 1.9]

Figure 3 (after Hoefman et al. 2014: fig. 1)

The study was conducted in the United States on a sample of 224 families (109 from New York and 115 from Arkansas). In most cases, there were two children in the families, one of them diagnosed with ASD, their average age being 8.4 years, 87% being boys. From the statistical data it was found that 97% of the families actually take care of the children; 61% of the respondents stated that they are having problems in daily tasks, 58% stated that they are experiencing mental problems and 52% physical problems, while 56% are facing financial problems; 40% of parents were experiencing severe depression. Despite these problems, parents said they were satisfied with how they manage to care for their child, scoring more than 7 on the scale of happiness (Hoefman et al., 2014).

Markowitz et al. (2016) conducted their research starting from an extremely relevant observation: quality of life is a complex, multidimensional concept, with systemic and bivalent functionality – the diagnosis, behavior, progress, health of the child affects the quality of life of his parents, while stress, parents' health problems, their isolation, their social stigmatization negatively affect the child's development. In order to evaluate simultaneously the quality of life of the child, parents, extended family and their external support system, the authors developed a tool they called the Child and Family Quality of Life (CFQL), meant to ensure a better understanding of the relationship between ASD and the quality of life. The questionnaire comprises 32 items, using a five step Likert scale measurement and evaluates seven areas, relevant for the child, but also for those close to him, namely: the child, the family, the caregiver, the relationship with the partner, the external support, adaptation and financial aspects. The sample consisted of parents of 212 children, aged 13 months to 7 years, who participated in an evaluation at a clinic in Cleveland, USA. The analysis of the data found a significantly lower quality of life for children with ASD, with the lowest values recorded in the domains: the child, the family, the caregiver, and the highest in the domains: financial, relationship with the partner and adaptation. A very interesting observation was that the families and especially the parents reported a decrease in the quality of life immediately after the diagnosis was found, probably aware of its negative impact.

An extremely interesting project took place in France, between 1997 and 2015. In order to identify the importance and the impact that the clinical, biological and environmental factors have on the evolution of children with pervasive developmental disorders (mainly ASD), a cohort (EpiTED) was created and subjected to periodic evaluations (at 5, 8, 15 and 20 years). The whole process is presented by the authors in the figure below.

On the occasion of the assessments made to the children at 15 and 20 years, the quality of life questionnaires were also applied to the parents. For evaluation, a standardized questionnaire was used, namely Parental – Developmental Disorder – Quality of Life (Par-DD-QoL), a tool that follows three dimensions, namely the emotional one, the daily affect and the overall quality of life. The questionnaire comprises 17 questions with five-step Likert scale answers; 15 questions concern the intensity of the difficulties encountered by the parents, the 16th the frequency, the last question referring to the parents' global vision on the quality of life (Rattaz et al., 2017: 2828-2830).

In the case of parents of young adults (20 years), statistical data showed that for 38.1% of them the diagnosis of the child has a strong impact on the quality of life, for 28.6% a moderate impact, and for 33.3% it has no an impact. 41% of parents experienced a high emotional impact, 27.6% moderately, and 31.4% did not experience an emotional impact. Overall, parents' quality of life was influenced by the child's abilities, severity of symptoms and disruptive behaviors (irritability, hyperactivity, lethargy) (Rattaz et al., 2017: 2831).

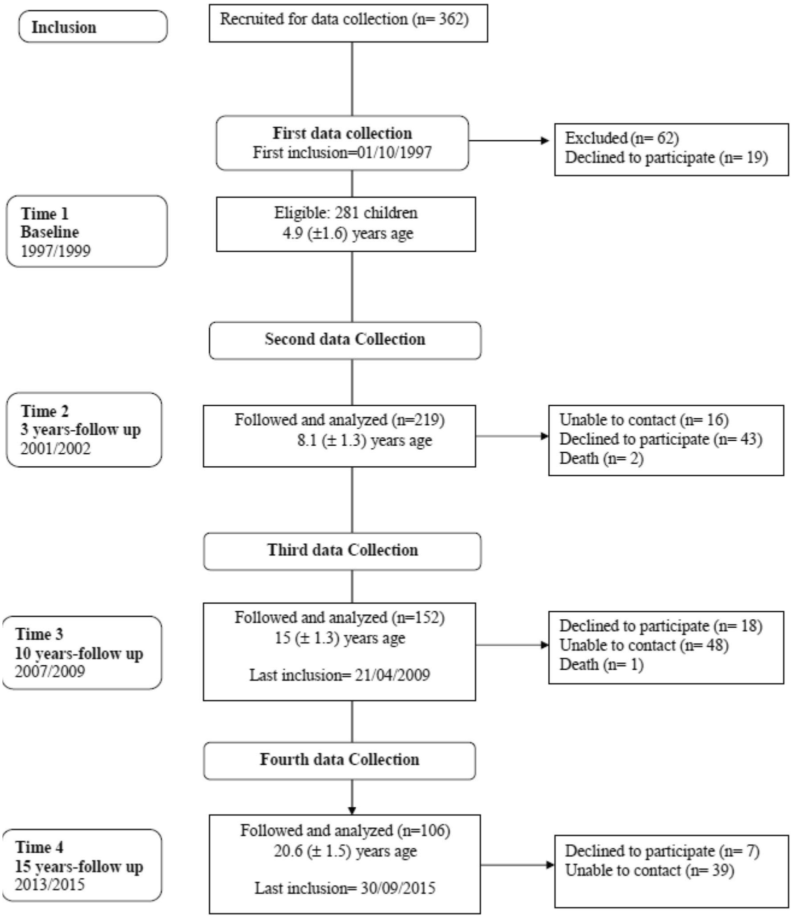


Figure 4 (after Rattaz et al., 2017: 2828, fig. 1)

Autism has a negative impact on the quality of life of parents including when the child reaches maturity, a fact revealed by the 2/3 percentage of parents who reported a high or moderate impact of the child's diagnosis on the quality of life (Rattaz et al., 2017: 2834). An important finding of the study was also that by evaluating the quality of life of the parents at a period of 5 years (at the age of the child of 15 and later 20 years), the recorded values did not change. The only changes found were related to disruptive behaviors, with a directly proportional influence on the quality of life, and also the main factor, reported by parents, which affects their quality of life once the child reaches maturity (in adolescence the quality of life of parents was impacted and of factors such as the child's level of development in terms of communication or personal autonomy). It could also be observed that the parents who received support from the support groups registered an increase in the quality of life (Rattaz et al., 2017: 2834-2835).

3. Researches on the quality of life of mothers with children with ASD

Researches undertaken to investigate the quality of life of mothers of children diagnosed with autism spectrum disorder have shown that in their case the level of stress and anxiety recorded is higher, while the level of satisfaction and social support have lower values than for the families of neurotypical children (Boyd, 2002).

The research carried out in Qatar mentioned above has shown that there are significant differences between men and women (with lower values in the case of women) regarding the values recorded in the indicators: fatigue, physical pain, low vitality, performance at the place of work, leisure, emotional problems. Overall, however, there are no statistically significant differences between the values recorded by women and men in the field of physical health (Kheir et al., 2012, 4).

Another study estimates that the lower values recorded by mothers of children with ASD, relative to fathers or mothers of neurotypical children, could have multiple explanations, from the time and resources they use in caring for the child with ASD and managing his disruptive behaviors, to the feeling of stigmatization that often stems from the social perception of the child, the lack of social or family support, the financial impact of the child's diagnosis, sometimes the behavioral problems of the neurotypical siblings of the child with ASD (Fairthorne et al., 2014: 666-667). The research was conducted in the suburbs of Perth (Australia), on a sample of 16 mothers with children with ASD and intellectual disabilities aged 11-24 years. Unlike most researches conducted to date, this was a qualitative research, which used a semi-structured interview (Fairthorne et al., 2014: 668). The responses of the mothers highlighted a poor quality of life, diagnosing the child having multiple negative consequences: job loss, divorce, deteriorating health, exclusion from the circles of friends (Fairthorne et al., 2014: 682).

Another qualitative research looked at the life situation of the mothers of children with autism in Norway. The semi-structured interview was used, applied to 6 mothers of children with ASD (3 boys and 3 girls) (Øien & Eisemann, 2016: 329). The study found that children's problems in communication, behavior and attention are the main factors that negatively affect the quality of life of mothers (Øien & Eisemann, 2016: 330).

One of the negative consequences that the diagnosis of a child with autism can have on parents, implicitly on the mother, is depression, which is the subject of a research carried out on a sample of 1110 people, of whom 540 suffer from depression (Zablotsky et al., 2013). The research used the Parental Depression History Questionnaire (PDHQ), which tracked the impact that the child's diagnosis has on the mother from the following perspectives: relationship with the partner, extended family relationships, social network, career, education and financial situation (Zablotsky et al., 2013: 1948). The results of the study highlighted the fact that mothers suffering from depression, unlike the others, have low values regarding the relationship with the partner and with the family, the financial situation and the career. The more severe the child's symptoms, with severe disruptive behaviors present, the lower the values recorded by mothers (Zablotsky et al., 2013: 1950).

Salehi et al. (2017) analyzed the quality of life of mothers with children with ASD in Tehran (Iran), assuming that in terms of quality of life they have the lowest values, compared to mothers of children diagnosed with other disorders. The instrument used was the same SF36 mentioned above. The study was conducted on a sample of 35 mothers, with children aged 3 to 7 years. Statistical analyzes revealed that there is a significant correlation between the severity of the diagnosis and the child's abilities and the quality of life of the mother (Salehi et al., 2017: 167).

Conclusions

The quality of life of children diagnosed with ASD and their parents, as a consequence of the child's diagnosis, is a topic in the concerns of researchers worldwide. Conducted not only for academic reasons, but with the stated purpose of supporting the development of the quality of services and social policies for this category of population, studies have shown, by comparison with control groups formed either from neurotypical subjects or from persons with other categories of disabilities or chronic conditions, the existence of significant statistical differences and of net inferior values of quality of life indicators for people suffering from / caring for children with autism spectrum disorder.

The lowest values of quality of life are recorded in the case of mothers, and they are also the ones that most frequently face health problems (especially mental ones-stress, depression, anxiety), due to the fact that child care is often a mother's concern.

Some studies have identified families who have come to know resilience, even rebuilding their lives despite the diagnosis of the child they still have to manage, even at maturity.

Another very interesting conclusion from the studies undertaken on young people with highly functional autism or Asperger's syndrome was that their perception of quality of life differs in a positive way from their parents' perception, and that their problems are not likely to affect their positive image about life.

Even though the vast majority of the studies we have reviewed have looked at the impact of autism on quality of life, especially from a socio-medical perspective (physical, mental-emotional health, relationships with partner, extended family or friends network), the conclusions reached after analyzing the results were almost unanimous: the autism of the child negatively impacts all aspects of the parents' lives, the higher or lower quality of life being influenced mainly by the severity of the disorder and especially by the presence and intensity of the disruptive behaviors of children.

Limits and future directions of research

A first limitation of this approach is that the synthesis is not an exhaustive one, for reasons already mentioned at the beginning, namely the extremely large number of studies undertaken to date, worldwide, to analyze the balance of autism on the quality of life.

A second limit, which represents at the same time a possible direction of research, is the fact that we have not documented the institutionalized resources (institutions, benefits, services in support of children with ASD and their parents) existing in the countries where there were carried out the researches, the perception and self-perception on the quality of life being considerably influenced by the health, education and social protection system that this category of population benefits from. Therefore, the quality of life research should not be analyzed strictly from the perspective of the impact of the diagnosis on the family, but also in correlation with the measures, services and benefits provided by the community, the state or the civil society to the child and his family.

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Third part

Studies on Autism Spectrum Disorder from National Contexts

Students with Autism Spectrum Disorder in Mainstream Classrooms in Italy.
Tackling the Challenge

Tamara Zappaterra[1]

Introduction

This chapter reflects on the principles, pedagogical theories and good practices that accompany the combination autism/schooling. Do all children with autism spectrum disorder go to school? What kind of school? Special school or ordinary school? These questions would be answered differently in different countries around the world. Concerning one of the most complex disorders to be diagnosed and addressed, the inclusion of affected students in school is not at all simple. This is partly because the actual application of the law concerning the education of young people with disabilities varies from country to country; thus their resulting education systems can be quite different from one another. Thus, it is not a straightforward process in every country for a family to include their child with autism in a regular school.

1. Disability and school inclusion in Italy. Theory and principles

In Italy has a 40-year tradition of the process that leading to inclusion of pupils with disabilities in regular school. In fact, a series of social benefit in Italy dating back to the mid-1970s led to acknowledgment that attendance by pupils with disabilities in ordinary educational facilities, in this case school, is of great democratic value. With Law 517 of 1977, Italy abolished differential classes and definitively ended what had been a period of educational segregation for students with disabilities (Trisciuzzi, 2002). There would no longer be two dis-

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tinct types of school, ordinary school and special school, the first for typically developing pupils and the second for pupils with atypical development, but from then on there was only one inclusive school open to all students and their differences (Trisciuzzi, 2002; Cottini & Morganti, 2015).

Therefore, egalitarian principles guided this decision in Italy -- the same principles that were only sanctioned internationally in 2006 with the UN "Convention on the Rights of Persons with Disabilities", which in Article 24 on Education, based on equality with others, invites signatory states to guarantee children and young people with disabilities an inclusive, quality education in their own communities. Today the inclusion of children with disabilities in ordinary schools has become an international standard and qualifies as a fundamental aim of a civil society (Trisciuzzi, 2002; Booth & Ainscow, 2002).

In Italy this progress was also approved for purely pedagogical-didactic reasons. The enactment of the aforementioned Law 517 of 1977 was preceded by a particularly fortunate period for Italian schools, consisting of experiments showing how including a child with disabilities in a regular class activated abilities that otherwise remained latent and that he/she achieved competencies in all areas of development, thanks to the quality and quantity of social interactions that only a context of typically developing peers could solicit (Zappaterra, 2014). In essence, it was observed that in highly stimulating contexts even children with severe learning difficulties activated what Vygotsky calls the "proximal development zone". This era in the schools was not well documented – which remains a great regret – however, these elements were supported by pedagogical and didactic studies in the subsequent decades.

At the same time, our concept of disability was changing its contours, up to the point of assuming and recognizing, in the definition itself, the role played by the person's environment. According to the so-called biopsychosocial model of disability of the World Health Organization, called the "International Classification of Functioning", a disability does not define the person, but is affected by the possibility of participation and inclusion in the environment in which this person interacts (WHO, 2001). While in the past we witnessed an inversely proportional relationship between the severity of a deficit and the possibility of inclusion of the person who was its bearer in their reference environment – that is to say, the greater the deficit, the lower the possibilities – today this ratio is fueled by complex interactions that include environmental and circumstantial variables.

Certainly family and school are among the most significant variables in determining the possibility of the social integration of people with disabilities in adult life. Being born into a family that has a certain awareness of the meaning and the problems of disability makes a big difference (Galanti & Sales, 2017). Equally, the school system in its conformation and its degree of acceptance of diversity is a very important element.

In Italy the school system is inclusive in the sense of that it welcomes all students, but it is also exclusive, in that there are no diversified educational pathways that allow families to make choices. In the Italian context, a child who manifests a disorder has to follow one and only one way – attending regular school, and participating in the educational experiences of everyone else, naturally with an appropriate personalization of the curriculum (Zappaterra, 2010; 2014; Cottini, 2017).

2. Students with autism spectrum disorder in the classroom. Critical aspects and good practices

There is no doubt that students with autism spectrum disorders face specific difficulties when placed in a regular class. Indeed, several intrinsic characteristics of this disorder work against inclusion in a school context. Specifically they are:

- Social interaction deficit (Kaat & Lecavalier, 2013): in people with autism the quality and quantity of social exchanges and ways of communicating can be very different from those of their peers.
- Intellectual functioning: in most cases we are faced with a pupil who has an intellectual deficit in addition to being on the autism spectrum. The difficulties are therefore more complex and articulated.
- Maladaptive behavior (Parson, Guldberg, MacLeod & Jones, 2009; Guldberg et al., 2011; Matson, 2014): the person with autism has stereotyped behaviors that are not coherent with the context (Barale & Ucelli, 2006). By the expression “maladaptive behavior” we refer to ways of reacting to certain stimuli that are completely inappropriate for that context, such as uncontrolled reactions of motility (throwing themselves on the ground, hitting the head against hard surfaces, or other body movements that injure themselves and/or others).

Although these characteristics are known to be typical of the behavior of many persons with autism and as such can invalidate the success of inclusion in a scholastic or social context, today inclusion is still possible.

However, in order to achieve real inclusion, it is necessary to overcome the old concept of integration, in which the pupil had to adapt to the needs of the environment. Instead, in the current concept of inclusion, there are environments, and therefore also schools, that are open to all the needs of the students, taking into account the fact that the student body is multiple and diversified. A school today should therefore be welcoming towards everyone and every individual. Regarding this aspect, Lucio Cottini pointed out that the student with autism spectrum disorder should not be considered a 'guest' who comes to the classroom from time to time, while the rest of his/her school-time is spent outside the classroom, in the corridor or in spaces specially equipped for him (2017). This student is an effective member of the class and as such must participate in the educational processes of the class and feel part of it. His right to learn is no different or less than that of his companions, so the teaching team must necessarily implement an adaptation of the curriculum that allows him to express his abilities, despite his peculiarities of behavior, interaction and learning. But before analyzing the adaptations of the curriculum that the literature indicates as effective, we wish to emphasize here the most important aspect – that is, direct contact with typically developing students and with all the teachers in an ordinary class represents for the student with autism an experience of inestimable value for the development of his/her potential, maturation as a person, and socialization skills. School is the most important microcosm environment of society, along with that of the family, for maturing into adult life (Dillon *et al.*, 2014; Galanti & Sales, 2017).

But let us discuss several critical aspects. The first aspect to keep in mind is the context. For a pupil with autism spectrum disorder the environment must necessarily be autism-friendly (McAllister & Sloan, 2017). When it comes to learning environments, nothing can ever be left to chance, because they must be functional for the intended purpose. If this is true for all pupils, it is particularly true for pupils with autism. The learning context for a student with autism becomes inclusive and effective if it has the following characteristics:

- The space is divided into specific areas for specific activities; whether it is a corner of the classroom, or a space outside the classroom, such as a laboratory for special activities, or other, that space must visually suggest the activities that one needs to accomplish

(Mesibov et al., 2007; Panerai et al., 2009; Cottini & Morganti, 2015). The student with autism has predominantly visual thinking and may have inadequate language ability, relating to either production or reception. Therefore, well-equipped environments reduce intervention by the adult teacher to a minimum by encouraging the student to concentrate on the activity to be performed (Parson, Guldberg, MacLeod & Jones, 2009; Fixsen et al., 2013).

- Learning is centered around Visual Teaching. This element is in perfect harmony with the previous one. A teaching method supported by iconic language (images, graphic organizers, visual work patterns) is highly compatible with the learning modalities of people with autism, and this type of didactic communication method is actually effective for all students, regardless of the presence or not of a learning difficulty (Mesibov et al., 2007; Mitchell, 2008; Panerai et al., 2009; Cottini & Morganti, 2015).
- The activities to be performed are predictable and understandable (NAC, 2009; Fixsen et al., 2013). This relates especially to the material used in the task or to the very nature of the activity. Children with autism prefer routine activities, where they are already familiar with the procedures. This does not mean that they must always be the same, but that the way they are carried out is known to them, and constitutes a shared script they can rely on. The level of difficulty and commitment in cognitive terms will always be determined by the teachers, in the context of creating a personalized path for the student. Therefore, activities are preferred where the possibility of error is reduced to a minimum, so that the student can have internal reinforcement and immediate feedback on the degree of adequacy of his abilities (Mesibov et al., 2007; Parson, Guldberg, MacLeod & Jones, 2009).
- The activities are repeated daily or weekly (Galanti & Sales, 2017). A balanced dose of routine activity is very useful for the student with autism, because this will help reduce the anxiety that is a trait that often arises when dealing with new tasks.
- The environment in which the educational activity takes place does not present distracting stimuli (Molteni, 2015). The classroom must contain only the tools and furnishings necessary to convey the teaching-learning process. Any other object or ornament is likely to distract the student or create communicative interference. The placement of the student's desk within the classroom should also be chosen based on the above criteria. The literature suggests identifying an environment within the classroom space where the

student can work individually, another in which he can work with a small group of companions, and still another location where he can work with the support teacher. Different spaces should be used for diversified activities with distinct educational purposes. This is why a fairly spacious classroom is suggested for classes that include a student with autism.

- The setting is real and not artificial. For some activities, real learning environments should be preferred whenever possible, since in such contexts the pupil's motivation to learn is stronger, and also because the student may not have sufficient ability to transfer any learning achieved in an artificial setting.
- The teacher carefully prepares not only the learning activities, but also the moments of transition between one activity and another, including moving from one place to another in the school. In fact, a student with autism always needs clear guidelines on how to behave and often this "empty" time is for him a time of crisis in which he not only does not know what to do, but does not know what behavior to adopt. Often at these times, which escape the direction of the teachers, students with autism become overwhelmed with sensory overload, an excess of visual and auditory stimuli (such as the noise and voices of their classmates), which can create significant difficulties in concentration, or cause them to have a meltdown (Bogdashina, 2016).

Therefore, an appropriate adaptation of the class curriculum is necessary, tailored to the particular needs of the student with autism (Rose, Meyer & Hitchcock, 2005; Hall, Meyer & Rose, 2012). There must be a didactic program for the class and ad hoc didactic programming for the pupil with autism. However, they must find points of contact, precisely as a result of Italy's decision on inclusion for all its students (Cottini, 2011; 2017).

In the debate on the inclusion of pupils with severe disabilities in regular classes, there is an open question regarding one aspect: is it more appropriate for these pupils to have their actual learning space inside or outside the classroom? The question would seem to contradict the inclusive choice. Not so, but in fact an explanation must be given. It should be emphasized that different spaces convey and support different learning skills and educational goals. Especially when considering a student with autism spectrum disorder with high cognitive functioning, sharing classroom space and participating in the same activities as their classmates is fundamental for learning social rules and for feeling they are an integral part of a community (Dawson, 2008; Mitchell, 2008; Reichow, Steiner & Volkmar, 2013; Cottini, 2017). Moreover, even in the case of a low-functioning autistic student, although sometimes the activities he performs are different from those of his companions, sharing the same space allows him to feel he is part of a group.

However, a situation that has the student with autism carry out activities outside the classroom has a certain pedagogical-didactic justification. Some activities take place in spaces designed for specific purposes, such as dedicated laboratories, or require a one-to-one relationship with the teacher or a companion, or activities that require sound isolation and the ability to interact with a limited number of people (Cottini, 2011). Sometimes this type of activity is preparatory to achieving a level of ability that subsequently allows the pupil to participate in the activities in class. Therefore, they are to be considered temporary or used less within the curriculum.

In any case, the equation that school time spent in the classroom is always inclusive, while time spent outside the classroom is not inclusive, is not valid (Cottini, 2017). Every aspect of the curriculum of a student with autism must be considered inclusive if the activities envisaged are identified as those most effective for his learning.

In addition, experts generally agree that the situation of a student with autism working exclusively with the support teacher is not pedagogically sustainable. If the choice to include students with disabilities in regular classes was based on pedagogical-didactic motivations and on the recognition of a right, it was also amply supported by the acknowledgment that a good part of the achievement of objectives is due to the stimulation of the context of their peers and therefore to socialization (Parson, Guldberg, MacLeod & Jones, 2009; Vivanti et al., 2014).

Sufficiently flexible forms of the curriculum must therefore be designed for each class, so as to be able to make any necessary adjustments for each type of student. Right from the planning stage, educational programming must be developed with content and learning objectives that can be developed in different ways and with differentiated communication codes – linguistic, visual, iconic – depending on the forms of preferred sensory input and cognitive abilities of every student (Olley & Reeve, 2004).

In cases of pupils with low-intellectual-functioning autism it will not always be possible to maintain for the individual those learning objectives designed for the class. However, it is desirable to maintain points of contact between the curricular programming of the class and that of the student, precisely because of the potential inherent in socialization among peers and in sharing and participating in the same training processes. If it is not possible to have the same learning objectives, one can at least make all the students work on the same content. It is possible to personalize the objectives and differentiate the activities, keeping the work of the student with autism in the same context as the content of his companions. This solution was defined by Cottini as participation in the "culture" of a task (2011; 2017). That is to say, if a pupil is unable to participate in the realization of a task, he will still be able to participate in the "culture" of that task with personalized activities, which will make him feel included in the context of the class group. These points of contact must be sought and planned for by the teachers, who must employ all their imagination and inventiveness.

In this regard, involvement in peer activity is very effective for the learning of pupils with autism as well as for raising their self-esteem (Reichow, Steiner & Volkmar, 2013; Matson, 2014; Zappaterra, 2014). Classmates prove to be a real resource to be used appropriately in the curriculum (Matson *et al.*, 2012; Cottini & Morganti, 2015). The most effective educational interventions for students with autism spectrum disorder include Cooperative Learning (Booth & Ainscow, 2002; Hall, Meyer & Rose, 2012). In these cases, this teaching methodology presents positive aspects in relation to the following aspects:

- Promotes social interaction between pupils, helping to decrease maladaptive behavior of the pupil with autism.
- Promotes improvement of the student's skills, especially regarding the development of communication skills and learning social rules, since in this way the student has the opportunity to closely observe the behavior of typically developing classmates, who can serve as a model.
- Promotes mutual understanding between peers and the development of welcoming attitudes on the part of all pupils, concerning the particular communication skills of the student with autism.
- Promotes the self-esteem and sense of self-efficacy of the student with autism who is called upon to make a personal contribution that is fundamental for the realization of the task entrusted to the whole group.

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Comparison of knowledge about autism spectrum disorders between students in Romania, Italy and Croatia

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Introduction

Research shows that there are many misconceptions about autism spectrum disorders among public but also professionals and students. There are different factors that contribute to those myths, misconceptions and stigma related to ASD.

Supporting persons with ASD requires teamwork using a collaborative approach. That means that team members are professionals within different areas of specialities. To ensure a positive outcome for persons with ASD and their families, each member needs to have training and knowledge to contribute to the team.

Incomplete knowledge about ASD was noted among college students in Great Britain (Shah, 2001), Nigeria (Igwe et al., 2010), US (Tipton & Blacher, 2014; Obeid et al., 2015) and Lebanon (Obeid et al., 2015).

Commonly reported misconceptions are related to aetiology (Alqahtani, 2012; Obeid et al., 2015), underestimating the prevalence of ASD (Dillenburger et al., 2013; Obeid et al., 2015), lack of knowledge about core diagnostic traits (Bakare et al., 2009; Kharti et al., 2011; Obeid et al., 2015) and support services (Chown, 2010; Imran et al., 2011).

Level of knowledge among students and professionals depends on different educational background, cultural context and experience with ASD.

Shah (2001) has evaluated a level of awareness about ASD among UK medical students at different stages of their training. Results show that fourth years students respond significantly more correct to questions related to diagnostic criteria and core symptoms. In accordance

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to those findings Shah suggested that training of medical students needs to be more focused on autism. That will improve diagnostic process as well as access to intervention. Level of physicians' knowledge about ASD has a great influence on his or her recognition of symptoms and the time/age in which diagnosis is set (Rhoades, Scarpa & Salley, 2007).

Schwartz and Drager (2008) stated that most of the school speech and language pathologists in thirty three states of USA had correct knowledge about the clinical presentations of ASD in children but mixed perceptions of diagnostic criteria despite the fact that most of them got information on ASD at some level of their educational training. Some of them stated that they would like to have additional training abut autism because they feel lack of confidence in direct work with children with ASD.

Igwe et al. (2010) conducted a study on 300 final year undergraduate students from department of Medicine, Nursing Science and Psychology, University of Nigeria, Enugu State with aim to investigate the level of knowledge and awareness about autism in childhood. The total score on questionnaire was positively correlated with number of weeks of posting in psychiatry and paediatrics. That means that medical and nursing students who spent more time in psychiatric and paediatric facilities then psychology students had better recognition of signs and symptoms of autism in childhood. Furthermore, total score was also positively correlated with the number of credit hours of lectures in psychiatry/abnormal psychology and paediatrics. In conclusion, the more credit hours of lecture and hours of exposure to the clinical experience the greater the student knowledge about ASD. In this study medical students had the highest mean score; they were followed by nursing students and psychology students who had the lowest score.

Tipton and Balcher (2014) conducted anonymous on- line survey of autism knowledge on undergraduate, graduate students, faculty and staff, in other words, of entire community of major South Western US university. They collected 1.057 surveys and 76% of participants had more correct answers then neutral or incorrect. Those respondents that had significantly more correct answers then others claimed to have someone with ASD in family. That finding argues in favour of the fact that immediate experience with persons with ASD increases knowledge about autism. Education and training on ASD for professionals should include practical and clinical work with people with ASD.

Through increasing knowledge about ASD it is possible to decrease misconceptions and stigma about ASD.

Cultural context and media also contribute to the existence of misconceptions and stereotypical perceptions of ASD. In countries in which ASD receives more public attention as well as research community attention it is probably easier to access correct information through education and experience. Countries that have political and economic stability can develop enough support services for people with ASD and promote their inclusion in society. No visible markers of ASD can contribute to public misconceptions about ASD because unknowledgeable people may perceive person with ASD to act purposely in the way that is not in accordance with social norms (Gray, 2002; Obeid et al., 2015). In countries that provide secure conditions for inclusion of people with ASD, there are greater opportunities for people with ASD and neurotypical people to meet each other, form friendships with each other and bridge their differences.

Obeid et al. (2015) conducted a study that compares knowledge and stigma associated with ASD among college students in Lebanon (N=329) and USA (N=346). Lebanon is a country with limited autism resources and on the other hand, US has considerable autism resources. Students completed assessments of knowledge and stigma before and after online ASD training. Lebanon students reported less overall knowledge and higher stigma towards ASD. Despite that fact Lebanon students were more knowledgeable about some specific aspects of ASD such as disparities in access to care then USA students. Online training about ASD correlates with increasing knowledge and decreasing stigma towards ASD in both groups of students. Authors conclude that online training may be cost-effective way to reduced misconceptions towards ASD. It could be a good way for both type of countries, those with limited support services for persons with ASD as well as for countries where considerable support exists but is unequally distributed (Obeid et al., 2015).

The main output of Erasmus + project Innovative Academic Course on Integrative Interventions for Children with Autism Spectrum Disorders within which this study was undertaking was to develop an academic course on ASD. The project is implemented by West University of Timisoara, Romain in partnership with University Lucian Blaga University of Sibiu, Romain, University of Florence, Italy and Faculty of Education and Rehabilitation Sciences, University of Zagreb, Croatia. These countries have some cultural differences, but also similarities.

Romania is a country located at the south-east of Central Europe. It is 12th largest country in the European Union. It has population of over 19 million inhabitants (National Institute of Statistics, 2019). Romania became a full member of European union in 2007 (Europa EU). 83,4% (World population review, 2019) of the country's people are ethnically Romanian and almost 82% (Index mundi, 2018) of the population are adherents of the Eastern Orthodox Church. According to Eurostat (2019) there are 35.7% of population at risk of poverty or social exclusion in Romania which makes it one of the highest risks in European Union.

Italy is a country situated in southern Europe. It has population of over 60 million (National Institute of Statistics, 2018). The dominant religion in Italy is Roman Catholicism and there is 80% of people who identify as Christians (World population review, 2019). Italy became member of European Union in 1958 (Europa EU). According to National Institute of Statistics (2018) in Italy over 1.8 million (7%) households lives in absolute poverty. Incidence of poverty by geographical area indicates that South Italy and Islands are the most affected (National Institute of Statistics, 2018).

Croatia is a young south-eastern European country with a population of just over 4 million. It was recognized as independent in 1992 and became a part of European Union in 2013. With over one million people (26.4% of the population) living in or at the edge of poverty (Eurostat, 2019), Croatia is one of the poorest countries in European Union. With over 90% of the population being ethnic Croats, the nation is highly homogenous (Croatian Bureau of Statistics, 2012). 85% of the population are roman Catholic (Croatian Bureau of Statistics, 2012).

The system of support for children with ASD and their families is still underdeveloped in those countries with the lack of professionals and ASD specific services.

The aim of this study was to detect knowledge of students and needs for improvements of their education. Students from different study programs participated in the project and this study. All those study programs are supposed to prepare students to become professionals that will work, besides others, with children and people with ASD.

1. Description of Study Programs

1.1. *West University of Timisoara, Romain*

Students that were participants of the project attended this study programs: Pedagogy (PEDA), Special Psychopedagogy (PPS) and Pedagogy of Primary and Pre-school Education (PIPP).

The Pedagogy specialization in the field of Educational Sciences, one of five such specializations existing at national level, is offered as a study program both at the level of initial training and level II of the master's cycle, by deepening in the fields of pedagogy: educational management, curriculum, educational counseling.

The mission of the PEDAGOGY specialization offered by the Department of Educational Sciences at the Faculty of Sociology and Psychology of the West University of Timisoara is to train pedagogical specialists able to offer qualified assistance for the design and development of any teaching and formative act, regardless of age, institution educational or educational context, formal or non-formal.

Possible occupations of future graduates: professor of psycho-pedagogical disciplines at pre-university and university level, professor of social sciences, educational counselor for school and career guidance, education and training specialist, educational programmer and educator, trainer in adult education, social pedagogue, training specialist in human resource development department, etc.

The Specialized psychopedagogy (PPS) specialization mission offered by the Department of Educational Sciences at the Faculty of Sociology and Psychology of the West University of Timisoara is to train specialists in Education Sciences with the Special Psychopedagogy. The Special Psychopedagogy specialization develops the following sets of professional competencies: designing and carrying out educational and training activities for children with special educational needs, psycho-pedagogical evaluation and special psychodiagnostics of people with special needs, designing psycho-pedagogical intervention and specific therapies, designing, psycho-pedagogical integration, integration of children with special educational needs in inclusive and inclusive schools and psycho-pedagogical counseling of children with special educational needs, their family and teachers involved in their education.

Possible professions after finishing this study program are: teacher-educator in special education; Special Education Teacher, speech therapist, support teacher; traveling instructor; psihodiagnostician; teacher of early education; pedagogue; professor of perceptual education-visual; school counselor; teacher for empowering children with school failure; professor of nongovernmental educational programs; a researcher in the field.

The mission of the Pedagogue of primary and practical education (PIPP) provided by the Department of Educational Sciences at the Faculty of Sociology and Psychology of the West University of Timisoara is to train specialists in education sciences with the qualification of primary and pre-school Education Pedagogy, capable of conceiving and to carry out specific didactic activities in an educational, formal or non-formal context. The PIPP specialization program has a pronounced interdisciplinary character, capitalizing on the knowledge of multiple fields such as: Romanian language and literature, didactics of language and communication, teaching of Romanian language and literature in primary education, mathematics, history, geography, didactics of these disciplines, pedagogy, psychology, special psycho-pedagogy, social pedagogy, sociology, through a multi-, inter- and transdisciplinary approach to education issues.

Within study programs on University of Timisoara there are no separate courses for autism spectrum disorders. Knowledge and competencies of students about ASD come from 2 courses: Multiple disabilities and Developmental disorders (West University of Timisoara, https://www.uvt.ro/en/).

1.2. *Lucian Blaga University of Sibiu*

Participants of this project attended Teacher Training Department within Faculty of Socio-Human Sciences in Lucian Blaga University of Sibiu. Degree programs are carried out in 2 main programs: Pedagogy of Primary and Preschool Education (in Romanian) and Pedagogy of Primary and Preschool Education (in German). Mission of this department is psycho-pedagogical and methodical preparation for students of all specializations and continuous training for teachers from the pre-university education. That means that, at present, any teacher in secondary, high school, post-secondary and higher education, in order to be able to practice, must take Level 1 and Level 2 courses. First level of the psycho-pedagogy module teaches students main concepts of their future profession: pedagogy, educational psychology, special didactics, classroom management and practical experience. Second level requires from students to demonstrate teaching skills, to prove their research skills in this field, to study adolescent, young and adult psycho-pedagogy, curricular area didactics, education project design and management and many other topics which can extend the educational and social skills necessary for the successful practice of the teaching profession. Within these programs, topics concerning ASD are covered through course of Special Psychopedagogy (Lucian Blaga University of Sibiu, http://socioumane.ulbsibiu.ro/dep.ppd/).

1.3. *University of Florence, Italy*

Participants of the project attended School Leadership and clinical pedagogy study program and Education Sciences.

The Master's Degree course, School leadership and clinical pedagogy, with its two profiles, aims to respond to the different types of personal services and aims to train professionals able to combine knowledge related to the organizational-managerial sphere with pedagogical, psychological and sociological knowledge. Professionals capable of interpreting the peculiarities of educational, re-educational and re-enabling systems aimed at the person, preventing their approval to economic-corporate one's tout court. Graduates in the master's degree program in School Leadership and Clinical Pedagogy can be defined as an educational leader, a training manager, an expert in the problems of discomfort and disability.

The degree course in Primary Education, divided into a single educational path without the division into addresses, promotes an advanced level of theoretical-practical training in the field of psycho-pedagogic, methodological-didactic, technological and research disciplines, aspects that characterize the professional profile of a nursery and primary school teacher. The CdS in fact enables teaching in the Nursery School and in the Primary School.

The Degree Course in Education Sciences allows you to acquire the knowledge and skills necessary to work in the field of formal education and non-formal education in the plurality of contexts that require specific preparation pedagogic. The CdS offers the necessary skills to carry out programming, implementation, management, evaluation of educational and training actions in public and private services and education and training systems from childhood to adulthood. The CdS intends to train a professional figure of Educator for childhood, adolescence and adulthood who responds to the increasingly complex demands of the world of work in the field of Services to the person throughout the entire life cycle: from early childhood, to special needs, to discomfort and marginality especially during the adolescent period, to the new forms of social deviance, to the different forms of discomfort, to the problems of the third/fourth age, but also to the new needs of education in adulthood.

Educator for early childhood: educators who intend to become involved in early childhood education services both in the nests system and in the diversified and rich framework of types of supplementary educational services for early childhood; they are educators who design and implement educational activities aimed at promoting psychic, cognitive and social development in preschool children.

Educator for adulthood and old age: educators who intend to work in the field of non-formal education of adults and the elderly with support functions in the planning and management of educational and training activities in dedicated training centers, in cooperatives social, in companies and organizations, in territorial educational services such as day centers, penitentiary institutes, reception centers for immigrants.

Educator for the inclusion of disability and youth distress: educators for services aimed at disability – from early childhood to adulthood, both in the school and outside the school environment – and services for social inclusion, for the prevention of discomfort – in particular to youth unease, marginality, deviance, gender, cultural and religious discrimination.

Within those study programs there are three courses in which topics about ASD are covered: Special education, Clinical pedagogy and Disability and rehabilitation psychology (University of Florence, https://www.unifi.it/changelang-eng.html).

1.4. *Faculty of Education and Rehabilitation Sciences (ERF), University of Zagreb, Croatia*

Students in the project attended the undergraduate study Rehabilitation which continues with study program Inclusive Education and Rehabilitation.

The programme of study is based on the basic knowledge in the interdisciplinary field of Educational Rehabilitation Sciences which implies all those processes and functions linked with visual impairments, learning difficulties, attention deficit/hyperactivity disorder (ADHD), intellectual disorders, disorders of the autistic spectrum, multiple difficulties, motoric disorders, chronic diseases (developmental motoric disorders, traumatism, autoimmune and malignant diseases, etc.), creative and art/expressive therapies.

Upon the completion of this study, the student acquires competences which make them eligible for employment on the tasks of medium complexity, i.e. under supervision of a holder of the MA degree, in accordance with the Act on Education and Rehabilitation Activities (National Gazette, no. 124, 2011).

Within the framework of the study programme of Rehabilitation, the holders of the BA degree acquire insight into the complementary concepts of the development of education and rehabilitation sciences and develop their professional identity in the following fields: visual impairments, motoric disorders, chronic diseases, and art therapy, as well as in inclusive education and rehabilitation.

Students acquire basis knowledge of diagnostic, educational, and therapeutic procedures, teamwork, professional ethics, and interdisciplinary communication.

Students come to understand the characteristics of the development and functioning in different environments, of both children and adults with intellectual disability, learning difficulties, attention deficit/ hyperactivity disorder (ADHD), autism spectrum disorder and multiple disabilities. They are qualified to conduct the assessment, create, implement and evaluate a support plan with the aim of improving the general functioning, and the functioning within various developmental areas of persons with disabilities.

There are 2 ASD courses in undergraduate and 2 courses on graduate study. Courses cover the theory and characteristics of ASD, teaching and intervention methods in lecture format and practical experiences with children and adults with ASD.

From previous section, it is clear that all study programs from four different universities and three countries prepare students for professions that will include providing support for persons with ASD. As mentioned, it is well established that professionals working with persons with ASD should have some specific knowledge and competencies. The aim of this study was to compare the knowledge about ASD and awareness of different approaches between students from different universities (Faculty of Education and Rehabilitation Sciences, http://www.erf.unizg.hr/hr/).

2. Method

2.1. *Participants*

As mentioned in previous section, participants of this study were Romanian students from Lucian Blaga University of Sibiu and West University of Timisoara, Italian students for University of Florence and Croatian students from University of Zagreb. The sample is convenient. They were receiving training on ASD within the European Union ERASMUS + project Innovative Academic Course on Integrative Interventions for Children with Autism Spectrum Disorders. There were in total 155 participants, mean age 22 years, 83% were female participants and 84% of participants attended undergraduate study. Information about participants from each University are presented in Table 1. Participants were students from various study programs that make them competent to work with typical children and children with disabilities in various settings (see introduction for more information on programs).

Table 1. Gender age and study level of participants

University	**N**	**Age (M)**	**Female**	**Male**	**Prefers not to say**	**Under graduate study**	**Graduate study**	**Post graduate study**
Lucian Blaga University of Sibiu	40	20	39	1	/	39	1	/
West University of Timisoara	37	23	36	1	/	32	5	/
University of Florence	40	25	37	/	3	21	16	3
University of Zagreb	38	20	37	1	/	38	/	/
All participants	155	22	149	3	3	130	22	3

2.2. Data collection

A Student questionnaire – *Knowledge and attitudes regarding ASD* was used. The questionnaire was adopted from teacher's questionnaire (Preece et al. 2018) used in another European project (ASD - EAST ERASMUS + project). The questionnaire had 3 sections. First section included questions about socio – demographic data and study programs (gender, age, name of the study, study level, courses on ASD, content of curses on ASD). Second section included statements about ASD and students had to express their agreement or disagreement with them. Statements included facts and myths about autism and for every correct answer participant has received 1 point. All points were then summed for each participant.

Third part included the list of specific approaches and students had to express how much they know about different methods (ABA, TEACCH, PECS etc.). Four-degree Likert scale was used ranging from no knowledge to I have a lot of knowledge. Questionnaires were delivered to students before the teaching activities of the IACIIC-ASD project started.

3. Results

3.1. *Knowledge about ASD*

One Way ANOVA was used to test the differences in knowledge regarding ASD. Results are shown in tables 2 and 3. There was a statistically significant difference in knowledge regarding ASD between students from different universities. Students from Croatia have achieved the highest mean score, followed by Italian, then students form Timisoara and students from Sibiu. That can maybe be explained by the fact that only students from University from Zagreb had at least one course specific to ASD and 50% of them had some practical experience with persons with ASD within those courses. So, this is in accordance with study by Igwe at al. (2010) in which persons with more clinical experience and credits had more knowledge. When we analyse results on statements (see table 4) we can see a lot of differences in agreement on specific statements between students form different universities.

Table 2. Descriptive statistics on points acquired on Knowledge about ASD variable

University	**N**	**Mean**	**SD**	**Std. Error**
Lucian Blaga University of Sibiu	43	8,7907	2,47423	,37732
West University of Timisoara	36	11,2222	2,82955	,47159
University of Florence	40	12,6250	1,97013	,31150
University of Zagreb	38	15,2895	1,90175	,30850
Total	157	11,8981	3,31311	,26442

Table 3. One-way ANOVA results - differences between students on Knowledge about autism variable

	Sum of Squares	df	Mean Square	F	Sig.
Between Groups	889,840	3	296,613	55,174	,000
Within Groups	822,529	153	5,376		
Total	1712,369	156			

While the majority of students from all universities agree that children with ASD can benefit from early intervention, that ASD is not the result of bad parenting, that children with ASD can be helped to have a better life and that they need special approaches, there are some statements in which there is a big discrepancy between students. While 95% of Croatian and 80% of Italian students agree that children with ASD can be educated alongside their typical peers, almost half of students from Sibiu don't agree with that. 74% of Sibiu students also agree that all students with ASD should be educated in special school while only 5% of students from Croatia and 7% of students from Italy agree with that. Since students from Sibiu will be preschool and primary teachers and work in mainstream conditions this is a worrying result. On the other hand, it is not a surprising result since during their education they only have one course on children with disabilities and few topics on ASD within that course.

Table 4. Some statements from Knowledge about autism variable

Statements	University of Zagreb	University of Florence	Lucian Blaga University of Sibiu	West University of Timisoara
Children with ASD benefit from early intervention	100%	90%	88%	86%
ASD is the result of the bad parenting	0%	3%	5%	3%
ASD can be cured	3%	15%	70%	45%
ASD cannot be cured but children can be helped to have a better life	100%	98%	79%	78%
Children with ASD are incapable of being educated alongside their mainstream peers	3%	15%	54%	15%
All children with ASD need specialist education approaches	82%	95%	97%	97%
All children with ASD need to be educated in special schools	5%	7%	74%	28%

Statements	**University of Zagreb**	**University of Florence**	**Lucian Blaga University of Sibiu**	**West University of Timisoara**
Children with ASD can be educated alongside their mainstream peers	95%	80%	51%	73%
Children can grow out of ASD	13%	60%	26%	44%
When children with ASD finally develop speech, all other difficulties disappear	3%	7%	44%	8%
Individuals with ASD can't live independently	32%	15%	61%	37%
Persons with ASD can have master or doctoral degree	92%	87%	35%	28%
All children with ASD have special gifts and talents in specific areas	19%	78%	90%	83%
Persons with ASD don't experience or show emotions	18%	25%	48%	34%

There is also a lack of knowledge about characteristic or heterogeneity in expression of ASD. 48% of students from Sibiu and the third of students from Timisoara agree that persons with ASD don't experience or show emotions, and 44% of students form Sibiu agree that when speech develops, there are no other challenges that persons with ASD have. Furthermore, 72% of students from Timisoara and 65% of students from Sibiu think that persons with ASD can't have master or doctoral degree and 61% of Sibiu students think that they can't live independently. It can also be explained by the lack of specific courses on ASD but also with the fact that children with ASD in Romania are mainly educated within the special system.

There are also differences on the statement that ASD can be cured, 70% of students form Sibiu and 45% of students from Timisoara think that ASD can be cured. Additionally, 60% of students from Italy and 44% of students from Timisoara believe that children can grow out of ASD. The first statement can imply that ASD is a disease, not a condition or a form of neurodiversity and second can imply that some children when they are growing up just stop having ASD. Recovery from autism is a very debatable subject. So far, the term "recovery" was used by researchers that evaluated intervention outcomes. It was used only as a result of a very intensive intervention. There is some evidence that some children do not present symptoms of ASD after that kind of intervention (eq. Fein et al., 2013; Seltzer et al., 2004). However, some studies have shown that those children still have a need for medical, therapeutic and educational support (eq. Mundy, 1993; Olsson, Westerlund, Lundstrom & Giacobini, 2015; Shulman et al., 2019) and that when years pass after the treatment some of them met criteria for ASD diagnosis again (Olsson et al. 2015). It is very important to be cautious in using the term recovery, cure or growing up from autism, especially in working with families. That can give false hopes to parents who can then only focus on recovery and in that situation, every other outcome would be a great disappointment for them.

3.2. *Knowledge about specific approaches*

In table 2 the percentage of students that have selected I have some knowledge and I have a lot of knowledge about the approach are presented. As expected, the results also vary between students from different universities. The highest percentage of students has a perception that they have knowledge about alternative and augmentative communication (AAC) system (Croatian and Italian students), followed by sensory based interventions (Croatian students), applied behaviour analysis (Croatian, Italian and Timisoara students), and expressive-art approaches (Croatian and Italian students). Students of Sibiu have the lowest results, with the highest result for sensory based approach (33%). This is understandable again because they don't have courses on ASD. Timisoara students have the highest result for ABA (78%), followed by expressive – art approaches (50%) and child – oriented approaches. Students from Italy have the highest results for AAC systems followed by ABA (72%), TEACCH (68%), expressive – art approaches (68%). Students from Croatia have the highest results for AAC systems (87%), followed by sensory – based approaches (83%), expressive – art approaches (79%), ABA (63%) and TEACCH (58%). Even though there is a lack of knowledge about ASD present among students, there are some high results on different approaches. This can be explained by the fact that some of those approaches (for example sensory based, expressive – art approaches, AAC and ABA) are not used exclusively for children with ASD. Students from Italy, Croatia and Timisoara have other courses that cover content about children with other disabilities for which those interventions can also be implemented. So, even though they are familiar with the approach it may be that they don't know how to use it with children with ASD. Croatian students that were participants of this study had only one introductory course before, and they will have 3 more courses on specific ASD strategies and interventions until they graduate.

Table 5. Percentage of students that have some or a lot of knowledge about specific approaches

Approaches	University of Zagreb, Croatia	University of Florence	Lucian Blaga University of Sibiu	West University of Timisoara
Sensory-based approaches	83%	30%	33%	41%
ABA - Applied Behaviour Analysis	63%	72%	23%	78%
Cognitive visual approaches TEACCH	58%	68%	16%	36%
Social stories	47%	30%	14%	33%
Alternative and augmentative communication systems; sign, PECS	87%	83%	28%	25%
Special diets	37%	10%	9%	25%
Drug/medication interventions	29%	8%	9%	29%
Child oriented approaches; DIR Floor time, Son Rise, Denver model	42%	20%	12%	47%
Expressive (art) approaches	79%	68%	26%	50%
Social skills groups	45%	33%	23%	29%
Peer support/peer mediated learning	47%	53%	9%	39%

Conclusion

Students that graduate on programs that will enable them to get employment in mainstream or special settings that provide educational or therapeutic approach for persons with ASD should have specific training and education on autism spectrum disorders. The result of this study has shown that there is a lack of knowledge on autism spectrum disorders among future professionals and that there are still some prejudices present. Professionals from West University of Timisoara and Lucan Blaga University of Sibiu have recognized the lack of courses on ASD within their study and formed a partnership with ERF, University of Zagreb and University of Florence to create curriculum and materials for such a course within the ERASMUS + international project Innovative Academic Course on Integrative Interventions for Children with Autism Spectrum Disorders. On ERF, University of Zagreb, there are 4 courses on ASD that cover, theory, interventions and practical experiences with persons with ASD of diverse abilities and ages. IACIIC-ASD will be a theoretical course but a very important beginning of development of ASD curriculum that will be incorporated in study programs of universities that still don't have such courses. This will empower future professionals for better understanding and supporting needs of persons with ASD and their families.

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Applied Behavior Analysis. The Romanian story

Loredana Al Ghazi, Damian Nedescu

“He is the father of the first Romanian child recovered from autism”.

This is the way the mass-media presents the man I virtually met 13 years ago on a forum. I was searching the internet for “autism in Romania”, preparing the next day course for my students, aiming to present the state of the affairs in the field. After two or three hours spent on autism.ro, I realized I discovered a treasure: it was much more there than questions and answers, much more than just parents sharing personal stories, asking and giving recommendations for specialists, or therapies, or fighting on them. There were scientific articles, the latest research results, books, Romanian translations of various resources, instruments for assessment… It took days to go through everything, cognitive and emotionally challenging, but I was in the state of flow reading, saving materials, taking notes. When I finished, I said to myself: those people are writing history here without even realizing that. A page of autism history in Romania, written by the people who lived it, not by academics or professionals of the field.

More than 15 years after the forum was created, one of its most active writers stands now right in front of me. It is not a nickname on the forum anymore, he is a real person with a real name: Damian. Damian Nedescu.

I am not sure how am I supposed to start the conversation. I am not a journalist, I am not a mother of a child on the spectrum, I am not a practitioner in the field, I am just a teacher/researcher interested in autism theory and history more than practice, so far. And then I remembered the subtitle of one of the most unique books on autism I have ever read: Adam Feinstein’s *History of autism. Conversations with the Pioneers.*

I told him I have this idea of writing a book chapter in Feinstein’s manner and he agreed. Maybe because it was something else than what he was used to: interviews for magazines, TV or radio programs and, more recently, writing on his blog or social media. The audience is different, the format is different, but the man enjoys differences and to be challenged. Finally, I decided not to interfere too much on the transcript inserting lots of references and footnotes. I let the pioneer to tell a story- about his child, about himself, about them as parents, their struggle and their victory, about ABA, about autism in Romania in the 2000s and nowadays.

People credit you with bringing Applied Behavioural Analysis in Romania (ABA). How did ABA get to Romania and how come Romania currently ranks among the first countries in the world in the field of applied behavioral analysis when it comes to the number of specialists relative to population?

It is not easy to explain. It was a combination of factors. First of all, it was the fact that Romania made a very early start on this route. Earlier than 95% of the countries in the European Union, even before Romania joined the Union. At that time, in 2002-2003, the only country in Europe with some activity in the field was the United Kingdom, which was following the overseas model. Using the same language as the US, it was infinitely easier to replicate a method. Romania somehow got in the way. Absolutely by chance. My child was diagnosed with infantile autism when he was about 2 and a half years old. In the next year and a half, approximately, we tried to find support from specialists in Romania. I mean, like any parent, not just from specialists. From everyone we hoped could offer us a solution. Almost blindly, like any desperate parent. Medicine, psychology, the church, bioenergy, medication or any alternative therapy. Or less therapy. I hardly missed anything.

And what was your experience with this mix of approaches? I ask because I imagine this is the path many parents still take Any kind of results?

Well, everything started extremely slow. Just like a diesel engine starts. From the beginning. In the sense that the first diagnosis came with difficulty. We had another child, five years older. The discrepancies between the development of the older versus the development of the young one raised our first suspicions. Then the pediatrician's suggestion to go to a specialist for a consultation gave us the first confirmation. At first, they tried to put off giving a diagnosis until the age of 5. I think that would have ultimately led to a disaster.

You mean delaying the diagnosis, or…

It's because, as I learned much later, neuroplasty of the brain drops sharply after the age of 7-8, approximately. It does not disappear but makes things much more complicated in changing behavioral reflexes. This is the reason why an early diagnosis can make the difference between success and failure.

Can you be more specific?

In the case of children and families of children with autism, I learned that the variables that can lead to a happy outcome are many. Some of them start with the age of diagnosis. As I said, brain neuroplasty drops drastically after the age of 7-8. This means that, metaphorically, before this age, if I have a nail in my hand, it is as if I were carving in a playdough ball. I can carve grooves. Deeper or more shallow, more complicated or simpler, I can focus on complex areas or focus only on certain things. After the child is 7, I have the same nail in my hand but instead of playdough I have a granite block. I can "scratch" and if I am determined enough, I can even carve deep grooves. But by no means can I stand the chance to get a sculpture out of it, as I would have liked. Now let's think mathematically. If I have this chance only up to 7 years old and if the minimum time for an ABA intervention covering most levels is about two years, it means that I would have to start intensive therapy somewhere around 4-5 years old, at the latest. Most parents need about a year to accept the diagnosis and start planning. Until then, there is a kind of denial or, at best, a passive acceptance of the situation. So if I do not have an extremely straightforward diagnosis before the child is maximum 40-48 months, the chances of that child having the option to recover or at least to reach his/her maximum potential decrease sharply. To speak frankly, they lean toward zero. Therefore, the age of diagnosis is crucial. That's why I say we were lucky to have an early first diagnosis. We, therefore, had the time to try everything else and, at the same time, to accept things as they were. It is not at all easy for parents to acknowledge the problem they have. Especially for dads.

Do you think there is a difference between the way a mother perceives a child's autism diagnosis and how a father perceives it?

Absolutely. Autism. Infantile autism. Autistic hints. Autistic elements. Atypical autism. ASD (autism spectrum disorders). All of them, diagnoses. Which each family perceives differently. Sometimes it happens, not infrequently, that even members of the same family perceive it differently. Mother one way, father another. Or vice versa. One of them is not aware of what is happening or has false hopes, thinking that, as the child grows up, the child will recover. On his/her own. Or that his/her own life will not change much in the years to come. I cannot make out if it is a matter of denial or somehow related to one's own comfort and the instinct of survival on the psychological level. I was the same. I know exactly. I could bring to my defense that, at that time, about 18 years ago, the existing level of information or the knowledge of the specialists leaned towards zero, as well. For whatever reason, my brain had the same reaction. On the grounds that it could not happen to me. I had a promising career, a wonderful family, other things to do. Autism? What the hell is that? My baby had a delay. So what? He will recover when he goes to kindergarten. In the first year after diagnosis I did go to doctors, specialists, therapists, etc. But without involvement. As if it had been part of a job. On my part, it was rather a kind of compromise so that I wouldn't argue with my wife. All this lasted until reality hit me. So that I was breathless.

Exactly what "hited" you? It was not the diagnosis per se…

The little one was about 3 1/2 years old when my mother-in-law found out in a newspaper that a foundation was setting up a kindergarten group for autistic children. They had received a grant from the World Bank and a year earlier they had formed a group for older autistic children. That year they wanted to try it out with preschoolers. Older autistic children, preschoolers?! I had no idea what these notions meant at that time except from the chronological age of my child. Said and done. I called and made an appointment sometime the following weekend. "Should we come with the child? No, that's not the case." Ok. The following Saturday we looked for the address, parked the car and walked a short distance. We stopped before a tall, green metal fence. Two buildings with a yard between them, everything closed within this forest enclosure, about 3 meters tall. Clean, painted, beautiful. We tried the gate. Nope. Locked. My wife was looking for the phone to call the lady we had talked to. She was dialing the number and I was ringing the doorbell like a white dot in the sea of green, which I noticed somewhere to the right of the gate. She is talking to the lady on the phone and almost at the same time, after a few moments, a click is heard and the door is unlocked. It will not open. But you feel it is no longer locked but barely open, a centimeter or two. My wife keeps talking and I smile and walk inside. From here on, everything becomes chaos. I took three steps in, to make room for her to enter behind me. I could not take a look around at all. Immediately a little girl embraced me. Almost a woman, actually. I found out later that she was 16 years old. If she had sat somewhere and hadn't said a word you would have guessed that she was a high school student. At least by the number of pimples on her forehead. Otherwise, cute. The average high school girl. She took me in her arms, put her head on my shoulder and started to babble something. I didn't understand what he was saying. But I was paralysed. Only my eyes were moving and I was looking around the yard. About two hundred square meters of courtyard between the two buildings we had seen from the street. Which, I then realized, were actually three building units. U-shaped. Within these two hundred meters there were about thirty or forty people. Of different ages. If you had had a magical remote control and you had pressed "pause" that is what you would have seen. 30-40 people, aged 15 to 50 years old, walking around the yard. It's just that… they were moving. And then you could notice the difference. About 20 of them were young. Very young. I found out later that they were between 14 and 25 years old. They displayed exactly the same behavior that my child had at 3 and a half! My child was completely non-verbal, he was wearing pampers, could not eat on his own, could not understand what he was told, could not dress or undress by himself, had dozens of stereotypes and self-stimulations. They were waving their hands, stared blankly at a wall or, on the contrary, looked like they were arguing with it, were running around the yard, had fun with a plush toy in their hand, were jumping, laughing alone. Zero interaction between them. That was the most striking aspect for you if you had watched them for a few minutes. And I had those few minutes, with the high-school girl, stuck on me. Then came two ladies. My wife was still petrified near the gate, making no gesture. Only big eyes, wide open, told the story of the storm in her mind. One of them gently took the high-school girl away from me and the other closed the door behind us, they smiled and one of them introduced herself as the manager of the center. In the two hours that followed, I stayed with the manager in one of the rooms inside. Overlooking the yard. I can't remember what she told us. I mean, I do know. I classified all the information she gave us about the group of preschoolers they were preparing and put it in the drawers of my mind. But my attention was focused elsewhere. I found out, among other things, that those in the yard were autistic children. Of different ages. And who had exactly the same acquisitions and behaviours as the little one I had at home. They had brought them together in a kind of group. Not a class. A group. They were doing activities together.

Some activities and somewhat together. In fact, they were trying to keep them happy for several hours a day. And give parents 4-5 hours of freedom every day. They could not do more for them. I asked if there were drugs or therapies or something. The lady there enumerated the medication that "children" in the yard were taking and some kinesiotherapy exercises and some other therapies. She also explained to me that there was no chance. But that we can keep our children happy. I had heard those words before. We left the place stone silent. Neither I nor my wife uttered a word until we got to the car. I drove to my house in a trance-like state. And there we looked at each other and each went to a different room. I think I needed a reset. We both did. Actually, I needed it most.That was the day I realized, empirically, as my mind could process at the moment, that it was not like a cold, that it does not wear off by itself, that my child would not evolve once taken to kindergarten, that he would not recover from exposure to the environment. That many years later, my child would communicate, maybe with a few extra words, at the age of 20, just like those adult children we saw in the yard. I didn't touch the subject at all that day. We made our plans for our child to attend that kindergarten group the following year. But nothing about what we had seen there and had terrified us both.

The next day, in the evening, before going to bed, we stopped in front of the bedroom and I said, out of the blue: "Our child will not end up like that. I'll get him back. He will get well." She didn't ask me what I meant. She didn't ask me how. She only asked me one question, looking into my eyes. "Do you promise?" And I said "YES". I had no idea how I was going to do it or what that meant. I just knew I had to find a solution. It was the day I woke up!

You woke up and you came with the plan of doing what? Starting where, going where?

Then it was the day I decided to do something in the most concrete way. We continued to look for solutions in Romania and then, step by step, to look into what was happening in Europe. But beyond a few regrets and dry explanations, no one in Europe had any solution. Except that, when he got older, we should send him to a sanatorium and, in the meantime, try to make another baby. The following year we got on the plane with the objective to find out what was happening in the United States in this field. Remember that we are talking about the beginning of internet times and the few companies that had survived the dot.com bubble were barely licking their wounds. It was the spring of 2003.

Did you bring specialists from the United States?

It's not that we didn't want to, but at the level of 2003, there were hardly any specialists even in the United States of America. Lovaas had published in 1987 the first study on the application of ABA to children with autism. With results that had blown away everything that was known about autism at that time. That is exactly why the scientific community was boldly challenging the results of Lovaas's 1987 study at UCLA. To put things together and to be considered in the most concrete way, approximately 26 studies were carried out over the next ten years, replicas to the initial study. On sites all over the world. The fact that the results of these multi-site replica studies were almost identical to those of the initial study made the world accept them. With reservations but they did accept them. The replicas of Lovaas's study were published in 97 '. Perhaps for most ordinary people, these few years that passed from the publication of the studies to the time when we landed in New York, in the spring of 2003, seem like an eternity. For the scientific and academic community a few years are a moment. So at that time, the concept of specialist in ABA did not exist in America, either. In 1998, the BACB certification appeared as, so to say, a niche issue. At the time, for example, there was no behavioral analyst in New York State. Or we didn't find any. It's not that we didn't know what we were looking for. Therefore, I took it methodically. I made a list of all the therapies that were in vogue and that were widespread at the time. TEACH and Son-rise were among the ones that attracted my attention most. And the ones we started to study in detail. Concepts. Then the testimonials. Then any article that referred to them. We took from the libraries all the books about these two therapies or any others that attracted our attention. This is how I came to study the journal of clinical psychology, for the sake of efficiency, and from one article to another I came across Lovaas's study in 1987. It struck me. Like a bucket of cold water after a night of heavy drinking. Because it was the first study that stated, black on white, that a child with autism can be recovered. A study, not a parent's testimony. This was the turning point and the first time I read about ABA. Then we started digging. Like archaeologists. I discovered Skinner and more from Lovaas, I went through everything. Again in bookshops or the library. Three months later, when we returned to Bucharest, three of the four huge suitcases we had were with books and printed articles about ABA and everything associated with it. Not necessarily ABA for autistic children but ABA in all forms and fields of application. Once we got home and studied everything we had taken with us, we realized that we needed a lot more information. But, above all, someone to guide us. So I ended up blaming myself that we didn't try to get to UCLA, at Lovaas department, when we were in the US. But I did it from Bucharest. I terrorized those at UCLA on the phone. Until I managed to talk to Lovaas. I explained exactly who I was and what I wanted. And he explained that he could not help me directly. Because geographically we were in different corners of the planet. But he gave me the contact details of one of his close collaborators, who had worked on the YAP (young autism project) and the studies done there, and who, in the meantime, had relocated to London. Diane Hayward, together with Professor Svein Eikeseth had founded UKYAP, one of the sites where the 1987 study was replicated, based in the United Kingdom. Diane was pregnant and was about to give birth but she agreed to send me one of the consultants she had available. Liz Shew. Who landed in Bucharest four months later.

So, in the end, you brought the specialists from the UK with whom you recovered your son?
Not really. Partially, to be more specific. It's actually much more complex. By the time we received approval from UKYAP we had already studied everything that had been published in the world on the topic of ABA at the time. I realized that the teams that participated in the studies were multidisciplinary teams in which each participant was an expert in his/her field. Moreover, the teams already had at least one or two people who had studied autism and had been specializing in behavioral analysis for many years. We did not have this time at our disposal. Let's specialize people. For us it was a fight against the clock even before the first consultant from UKYAP set foot in Romania. Therefore, we got a head start. We hired about twenty people, as soon as I had the exact date when Liz was about to land.

Specialized in ABA? Or in psychology? Or what kind of professionals?
In theory, yes. Or so we wished. That is, I posted ads in the most popular newspapers, looking for graduates in psychology to work with an autistic child. The experience was not required, and training was free. I received hundreds of CVs because the post itself proliferated the concept of team. Then we started to build. The advantage I had was that I had no budget constraints and that I had experience building teams. Not in this field, but I had already built more than twenty teams in my career, in different fields, in different companies,

local or multinational. I set the criteria for those we wanted to choose, and I started to run interviews. In a couple of weeks, I saw about a hundred people. I chose about 20. I invited them home, to some kind of a trial. I mean I had them play with the child for two hours.

What were your criteria of choice?

The irony is that I deviated significantly from the criteria, from the first moment. In the sense that, in the initial 20 people team, I chose a psychology graduate who did not know English at all, a graduate of a faculty of economics who was head of a store at a supermarket, a medicine graduate who had never worked in the field because her husband was a diplomat by profession, a national martial arts champion and so on. In fact, the true selection criteria appeared in the weeks when everyone had to come at our house and play with the child. Each had two such meetings. I cut off the shortlist all those who were late. Even if it was only for 1 minute or if the explanations and reasons for the delay were extremely relevant. I excluded them because we knew that time was our worst enemy. In our case, minutes could make a difference. The second criterion was the one related to how they were played. Imagination and effervescence were very important. But even more, the number of attempts and the determination to try again, even if the child rejected them mattered more. In at least in two cases I chose determination despite lack of imagination. Two weeks later nine remained. At the end of the first month only six. Then I took out the most important studies and books about ABA as an approach. And each member of the team had to read from one day to another a chapter or study, and then explain it to the others in the team. In fact, I kept this system for the next year and a half.

What about you, the parents?

What about us? We were part of the team. We were doing what the others were doing. Everything. We had our hours of working with the child, playing, while the others were watching us on the monitor, from the room next to us. And we were reading a chapter and explaining it to the team the next day, and we maintained the same rigour that we subjected them to. In everything we were doing.

Were you filming what you were doing?

Everything. Without exception. I filmed everything. Basically, almost six months before Liz came and even before we hired the 20 people, we installed a camera in the office where the sessions would take place. And from that moment nothing that happened to the little one was missed, nothing happened without filming or collecting data.

How many hours of therapy were you doing?

Basically … all day. Theoretically, 40 hours a week. In the 1987 study, the YAP (young autism project) teams made public the number of hours in session with children in the study. Respectively, between 20 and 60 hours per week with each. The average per week was 40 hours. Therefore we took this number of hours as reference. That was the theory. Practically, the whole team came in the morning, at 8 o'clock at our house and they all stayed until late at night. 20.00 P.M. most of the time. After that, we, the family, were leading our normal life. But with the precepts of ABA running through our veins. Basically, the little one, beyond the therapy itself, was involved in various activities and supervised continuously. If we view this under the incidental teaching prism, we were doing ABA with the child after the therapy hours were over. ABA became a way of life for us. Therefore, the answer to your question is: all the time. Especially in the first year of therapy, it wasn't just therapy at all. It was schooling for us all, the team. And a reconsideration of our whole family life.

As a family, has your life changed?

Completely. In fact, everything that happened was a conversion of all the activities in the house, starting from his needs. And those of the team. We haven't forgotten, not for a second, that we all had to learn. Again, beyond the fight with Radu's disability, our struggle was against time. We had time to recover him before he was 7. Two years. In these two years we had to help our child to recover the gap. But in order to do that, I needed a team that had to become immensely experienced. In an extremely short time. I set the pace. Intensive. Because time was not on our side at all. So I built a whole system. To have a chance. This meant that all the therapists, together with us, started the program early every morning at 9 am and ended in the evening, around 8 pm or 9 pm. It didn't matter if on that day only two or three or four of the therapists were on call. We were all there. Physically. Watching on the monitor from another room what teams of two therapists were working inside. That way the feedback I got from each hour was instant. Basically, every hour of therapy became another hour of experience for everyone in the team. That was also my biggest gain. About a year after I started the therapy I had the right team and they worked clean. Applied behavioral analysis.

What happened next?

The London consultant from UKYAP came to us every 2 or 3 months. Usually she gave us on average about 40 programs. Some in the current session and about half new programs, to be introduced after we used the current ones in generalization.

What is the difference between a current program and a generalization program?

Applied behavioral analysis creates new patterns of behavior. Some of them are somewhat mechanically introduced, actually grinding the needs of the child or sometimes creating that need. The ultimate goal is that everything the child learns can be used in everyday life. Only then can you consider that a program is a mastered. When the society itself and the context become rewarding for the child. In fact, in ABA you teach the child to learn. You cannot say that you have a mastered program before the child is able to take things alone from the environment and learn them. Therefore, both items and programs are mastered. First of all in any form you chose to teach it to the child and then in generalization. Generalization means that the respective child will demonstrate the learned ability, in any context, with anyone, regardless of location. That is, it becomes intrinsic and natural to the child.

So she gave you about 40 programs every few months. What happened next?

At one point, after about a year of therapy, we had become so good and knew the child so well that not we not only finished everything the consultant gave us, but we invented new programs, created based on the needs of the little one. Based on Liz's last two visits, almost two years after we started therapy, at one point she told us straight: "At this moment, as far as Radu is concerned, I simply don't have anything else to teach you. Moreover, I started taking elements from the programs you created and I use them for other children. You're already paying me for nothing".

It was the moment when we understood that our adventure and our struggle with autism regarding our child, was coming to an end.

Was that all?

Not even close. A few months later, somewhere through the fall of 2005, I arranged a few assessments. Actually two in Romania. Two teams of psychologists who did not know one another were asked to evaluate Radu, without knowing anything about his history. Zero anamneses. The first team evaluated him at our home for three days and the second, at their office, for two days. The results of the reports, one week later: no trace of autism. In one of the reports there was a note related to a slight attention deficit. Then we got on the plane and did another evaluation in London, at the clinic of one of the most reputable psychiatrists. The result of the report identical to those of Bucharest: no trace of autism. It was only at that moment that we relaxed and confirmed what we sensed: we had been through the hardest part. And Radu was probably the first child recovered from childhood autism in southeastern Europe. The reactions of the teams that evaluated him were amusing. While the team of doctors and psychologists in London, when told about his diagnosis two years before, after reading the documents said only so much: “you made a heck of a job!”, the first reaction of the teams in Romania was: “I think he was misdiagnosed!”. Not even the 7 diagnoses and 3 certificates of severe handicap made them change their minds. It wasn’t until they saw the videos of Radu’s first therapy session that they were “wow, we didn’t think that was possible!”

And then what else happened?

With Radu? A lot. In the sense that we continued the run. Yes, from the medical point of view he no longer met the criteria for autism. Not at all. But he still had big problems in social, emotional, contextual, etc. areas. Therefore, we became aware that he was recovered in a proportion of 98%. The other 2% took us another 7 or 8 years. About the time Radu got into high school.

Still ABA?

Not. Or, I mean, not as intense and structured. ABA is the science of human behaviour. It has nothing to do with autism. That is, we all, regardless of context, operate on the basis of A-B-C (antecedent-behavior-consequence). That’s how we learn, that’s how we live our life, based on it. Every day. So, looking at it from this perspective, yes, still with ABA. But moving on to a more holistic approach and exposing him to as many experiences as possible. The theory of mind was the next path we followed and from which we extracted most of the exercises and directions we used in the following years.

Was he accompanied by a therapist at school? As you said, everything lasted until he enrolled in high school.

He was accompanied by a therapist all the time. Starting from kindergarten, through the second or third grade. Obviously, as the time went by, the therapist's involvement lessened. Often, in the end, we only had a camera set in a corner of the classroom and we filmed everything. The therapist only went to retrieve the footage from each day. And when the high school topic came up, although from kindergarten to school he studied in the private environment, I decided that the next step would be to enter the state system of mass education, without anyone knowing anything about his history. I paved the way a bit, it's true, but I let things flow naturally.

In what sense have you paved the way?
From the first moment, when I chose the high schools he could attend, I chose the high schools that had by definition many girls. Girls are more tolerant. Considering his affinities to academic subjects, I chose the high school 'Iulia Hasdeu'. Philology and History. And that's how Radu came to study philosophy in Belgium.

How was it in high school?
Like any other high school kid. Or a student's life in a high school.

You mean nobody knew about Radu's condition?
That's right, no one knew. Neither his teachers, nor his colleagues. In fact, his girlfriend at that time learned of his history in a PROTV feature from the summer of 2018.

So, going back to the initial question, how was ABA introduced in Romania?
About 7-8 months after we started the first ABA workshop with Liz Shew, we realized that we were on the right track. We were lucky. Or Radu was lucky. One way or another the stars aligned for him. We were part of the lucky ones: the financial situation allowed us everything, both me and Cristina had the managerial experience to manage multidisciplinary teams and I was extremely experienced in creating new projects and giving them life. Therefore, we were able to do what no other family either afforded or they simply failed. But we, like others, have climbed the agonizing hill of the Romanian health system for about two and a half years. Therefore, we wondered, if it had been so complicated for us, what chance is there for any family? The answer came promptly and quickly, beyond any doubt: zero chances. So I felt it was our duty to give something back to society.

How did that actually happen?

The first time I tried the … easy way. I contacted two associations that were already involved in the field of autism and I made a proposal to finance them and offer them directions and how to do it, how to specialize, etc. It's just that … the two experiences were hallucinating.

What do you mean?

I mean, the first association had received a grant from the World Bank to publish a specialised journal in the field of autism. Not about behavioral analysis but about autism in general. I did not fully agree with the editorial content because it rather promoted the idea of support for parents and palliative therapy. But I considered it an informative environment for families. So I proposed to them to carry on publishing the magazine even after the grant was over. They had received a grant that funded the first 4 magazine issues. We submitted an offer to them in which we undertook the editing and printing, as well as the distribution. The only thing they had to do was write or receive materials. Content therefore. They told us no, that was not enough. They wanted money. "How else do we show our sponsors that we can raise money?", they said. I was silent. They preferred to give up publishing the magazine rather than us funding the indirect services. They wanted the money. The second experience was even worse. We went to the center where Radu had been a resident for several months and we proposed to the decision makers there to fund them and at the same time to help them bring in specialists from outside and specialize their people in ABA. Moreover, I brought them all the books and documents, studies, Radu's personalized intervention plans, videos of Radu, etc. Everything. They agreed and we started a fundraising campaign where both our companies and business partners and friends started donating money in excess of a 5 zero sum. In Euros. Reality hit us a few months later when two things happened. The clinical director of the association, a psychologist lady who had constantly opposed the introduction of ABA at the start, published a book based on all the information and documents we had made available to her, claiming them them as if they had been hers. Including there even fragments of Radu's intervention plan, as if she had created it herself. The second thing was an audit that I ordered, naturally for the finances of the respective association, because in one way or another I had guaranteed the fun raising with my name. I was shocked when I saw that 25 thousand euros were missing from the amount raised. And to my question where the money was, I was nonchalantly answered that gifts were purchased for the members of the association! I was perplexed. Those people did not understand that the money was raised for the children and to fund programs for them, not for Christmas gifts for the members of the association. It was the moment when I decided that it was healthier to create something that would support the interests of the little ones and make a difference.

Was this "something" the Horia Motoi center?

Not realy. This "something" was "The Pilot Project for Helping of Children with Autism in Romania". A project that initiated the autism.ro site, information campaigns, the Horia Motoi center, a law for the settlement of therapies, lobby to decrease the age of diagnosis of children with autism (in the US a diagnosis could placed from 18 months while in Romania no doctor wanted to give this diagnosis until the child was 5-6 years old), it brought a course approved by ABAI in Romania, respectively BCBA (Behavior Analyst Certification Board - international forum for the certification of behavioral analysts) and a few other projects which supported the development of ABA applications and interventions in children with autism.

I think it's a natural question: who was or what does Horia Motoi come from?

Horia Motoi is my grandfather's name. The one who raised me and instilled in me a certain conduct. He loved children deeply. It's a tribute to him.

I noticed you never say "ABA therapy"...

ABA – applied behavioral analysis – is a science that studies human behavior. It has become a science for many years and is not related to autism. Or with children with ASD. That is why I am away from calling it therapy. ABA is the science of human behavior viewed strictly from the perspective of behavior, without other embellishments. It is related to psychology in a way but it has gained independence long ago and it is another line.

What do you mean "without other embellishments"?

As I see it, psychology links emotional chemistry to certain behaviors. ABA, as a science, ignores anything that cannot be measured. When you say "I was angry and I threw the glass at the wall", a psychologist will focus on the question "why were you nervous?" A behavioral analyst will focus on "I threw the glass at the wall". That is because he cannot measure "anger". This means that they start collecting data: how many times do you throw the glass at the wall a week, at what times, what is the context in which you do it, what is the function of the behavior of throwing the glass, etc. From the perspective of behavioral analysis, a behavior, any behavior, has dimensions. Like a closet: height, depth, width, etc. If I want to furnish my bedroom and I want a closet, I don't just go to the store to buy a closet. I go to the store with the dimensions of the closet I want. Otherwise I have all the chances that the closet I order won't even fir through the door, not just not fit in the place I planned. So are behaviors. They have dimensions and functions. Frequency, strength, intensity and obviously, although not a size, a function. Like any piece of furniture. In the end, behaviors are the furniture from our "attic".

Well, and what about emotions, cognitions?

That's what I was saying: what you do with "being angry" is the psychologist's job. The task of the behavioral analyst is to make you have another type of behavior when you are nervous and for example not to throw the glass at the wall. Because that's the essence of behavioral analysis. The study of human behaviors begins with the way people learn and acquire certain behaviors, ever since they are born. Until they close their eyes. We are an adaptive species, which is constantly learning. ABA is studying this. How people learn, acquire and fix behaviors. And how, in effect, adjustments can be made to ways of learning so as to change behaviors or learn to use certain behaviors faster.

Of course, ABA as a science has a lot of practical applicability but people associate it instantly with autism…

That's right. It's been used for decades in organizations, human resources departments, army organizations, secret services or police, corporations, the field of ecology to change the behaviors of those who live in a certain area to take more care of the environment, in the area of AI (artificial intelligence) to learn faster, etc. Of the ABA component that refers to the study of how humans are learning, one of the applications refers to children with ASD. This is why I have been lately avoiding the term 'therapy' and I prefer 'intervention'.

Resuming, what does the application of ABA mean for children with ASD?

ABA intervention in children with ASD is actually the line of ABA that deals with studying the acceleration of learning models in humans. Because ABA intervention in children with TSA (autism spectrum disorder) is focused on accelerating the learning of skills to the point where a child with autism regains behaviors and abilities so s/he can no longer be distinguished from a neurotypical child.

So, can autism, or ASD, as it is now called, be cured?

Autism or ASD is not a disease. So by definition you cannot "cure" it. Because, as I said before, there is nothing to heal. Physiologically there is no difference between a neurotypical child and a child with ASD. Lets say, from a physiological point of view, they are perfectly normal. The mechanism that does not work in their case is the one through which we, neurotypicals, learn. Therefore, as time goes by, the neurotypical child learns from the environment and thus develops all kinds of new skills while the child with ASD does not learn and therefore remains increasingly behind. So much so that s/he can never reach the neurotypical one if he failed to balance the set of skills acquired until around the age of 7.

So I understand that ABA as an intervention is really nothing more than a form or a teaching technique?

Yes, essentially, it is. We humans work when it comes to learning, from early childhood, in an ABC system - antecedent - behavior - consequence. That is, we learn any new behavior (ability) based on this principle. The antecedent is everything that has happened until then in our life regarding that behavior and the consequence is the natural thing that happens if we have that behavior. More precisely, if we listen to our parents when they tell us not to stick a nail in the socket, it means that behavior, sticking a nail in the socket, does not appear. So, the fact that they told us and we listened to them means that they have altered our antecedent. Therefore our behavior was changed and, even if we wanted to, we never stuck the nail in the socket. If, on the contrary, we stuck the nail in the socket and we were electrocuted (pain), next time we will use the consequence as an antecedent and we will change our behavior. The same applies to the way we learn other things, like, for example, we like cakes. In fact, we learn about everything and everything in the same way. Unfortunately, the child with ASD does not learn at the same rate as a neurotypical child. In fact, the difference between the learning speed of a child with ASD and a neurotypical child is huge. In one day, a child has on average about a thousand learning opportunities. While the neurotypical child gets about 30-40 of them every day, in most cases, the child with ASD gets 2-3 per month. As time goes by, the discrepancy between what a neurotypical child knows and what a ASD child knows, is huge. The ABA intervention focuses in particular on increasing the acquisition speed of new skills of the child with ASD. This thing is personalized. Because every child with ASD is completely different from another. Therefore, the whole plan and strategy to follow in order to accelerate his/her learning speed is specially designed for the child to whom it is addressed. It is not a general issue applicable to all children with ASD. That is why I am not calling it therapy. Because it's not. It's not even a teaching technique, since you were mentioning it. It is a science and a combination of teaching and intervention techniques to maximize the learning speed of a particular child with ASD.

Then lets put it this way: ABA is the science that studies human behavior. Do you think that ABA is the first intervention that is suggested as soon as a child is diagnosed with ASD, in Romania. How come?

Yes, according to the latest studies, in Romania, the first suggested intervention (80.6% - Salomone et al., 2014) for children with ASD is ABA. It's not just in Romania. In the USA it has been the first recommended intervention in young children with ASD for years. Moreover, in 39 states out of 52, it is not only suggested, it is also fully settled. In fact, it all started about 15 years ago in the most serious way. When American insurance companies made a simple calculation: a child who becomes an adult with ASD costs $30-50 thousand a year. Throughout his entire life, that means between 2.5 and 4 million dollars. If a percentage, some percentage of these children can recover, it means not only that they no longer pay, so they save millions, but they manage to integrate them into the system and naturally, the recovered adult will pay taxes to the insurance companies. It's a strictly economic calculation. A calculation of economic efficiency. This is how a lot of money from insurance companies has been directed towards various studies in this field so that the intervention methods can be refined and become more efficient. There were no studies in Romania. But the legend that Radu became illuminated the path of many families. Obviously, besides the professionals, there were those who read two books and made from ABA only a commercial product to serve to the parents. But what they do is not related to ABA. For the simple reason that they have no training in this field. They graduated from the faculty of psychology and are applying some psycho-pedagogy of recovery with certain ABA concepts that they consider effective. Obviously, this makes the intervention totally ineffective in its essence but … this is a completely different story.

Still there are recovered children in Romania. And the field is growing more and more.

Indeed, there are. Many. I do not think that anyone has reached or come close to Lovaas' percentage or the replica studies after him, respectively 47%. We are talking about only a few hundred children recovered in Romania over the last 15 years, although every year, according to statistics and the incidence rate in the country, about 3500 children with ASD are born annually. It is an ocean in a sea of despair but there is a chance. And the field is developing. Quite strongly. But it is a field with sustained development and, in the absence of determination and greed, to be constantly up to date with the news in the field, you have every chance to lag behind.

What do you plan to renovate or innovate in the field in the coming years?

I haven't planned anything sine die. I don't even think it's something that you have to plan. It just happens. Or it doesn't. I would be happier if the number of specialists completing postgraduate training in behavioral analysis increasled significantly in the next 5-7 years. Because, a few hundred behavioral analysts could really make a difference in the cascade of children with ASD. Only then would the critical mass that could generate the change in society regarding Autistic Spectrum Disorder appear. Furthermore, we have the DAAL Autism Project which aims not only to replicate the Lovaas and Ronald Leaf's studies, but also to offer courses and seminars addressed directly to the beneficiaries so that the rate of the parents' involvement increases substantially.

What do you think about bringing ABA in the Romanian universities? I mean what would be like to provide ABA training at an academic level, as many US and some UE universities do?

Romania happened to be among the first countries in the world where ABA was successfully implemented. Introducing the study of the behavioral analysis in the academic environment, in the Romanian universities, under the incidence of the academic arm of the BACB (Behavior Analyst Certification Board), respectively ABAI (Association for Behavior Analysis International), of a VCS course (verified course sequence), is the next step, most naturally, in the creation of tomorrow's specialists, with extremely well-grounded training in ABA. Behavioral analysis is a science and training in science, to become the professional tomorrow specialist, to make a difference for children with ASD, cannot be done other than in the academic environment, respecting the standards imposed by the globally recognized forum (BACB). This is how it happens all over the world and Romania and it cannot do otherwise if we think about tomorrow's generations. And with this natural step, the foundation is established for research programs and for covering the huge need of specialists in the field.

I will do my best to make this happen, as a premiere for Romania, at the West University in Timisoara. Can I count on your help?

Well, the story must go on!

Thank you! And let's then close our conversation in an optimistic tone…

Smiling: "To be continued…"?

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