

I. DEFINITION

Autism Spectrum Disorders are characterized by hampered social interactions, restricted interests, and a number of stereotypical behaviors. In this clinical portrait, to which is now added an altered sensory and perceptive profile, the DSM V [1] re-integrated Asperger's Syndrome within the Autism Spectrum Disorders (ASD) category, no longer defining it as a specific category but relocating it at the extreme positive end of a continuum of all ASDs.

In its neuropsychological aspect, autism lists both a functioning of perception and a cognitive processing of information which are particularly complicated by the inability to understand and integrate the thoughts and behaviors of others [2-4], and this in a context in which the processing and integration of dynamic information is impaired [5-6], and conditioned by a context blindness – caetexia [10-13].

This deep inability to understand the complexity of the dynamic environment in its entirety leads to an emotional, cognitive, and behavioral maladjustment which is a significant handicap in terms of social adaptation.

ISSUE: Why has research only recently become interested in the issue of undiagnosed adults with autism?

Generally, autism is almost always associated with childhood or a younger population, because there are so many questions remaining about the future of these individuals and so many areas still ripe for exploration in this field; there is a subtle idea, however, that autism without intellectual disabilities somehow miraculously disappears at puberty, grows less pronounced, or that the person with autism “normalizes” as time passes, or is even cured, either on their own or through various support methods. Worse yet, it is somewhat like there is nothing more to do once the early years have passed, regardless the original severity of the disorder. This is definitely false because autism is an irreversible neurobiological condition from which a person is not cured, and which will remain a part of the individual's entire life. But the autism doesn't impede the individual's capacity to evolve, which is why it is so important to care for person on the autism spectrum throughout their entire life and not only during childhood.

And why has science only very recently focused on the question of previously undiagnosed autism in adulthood? Which is to say adults living with autism spectrum, since the other two categories are identifiable and therefore identified? Well, this involves admitting that they were not detected, or that they were given a different and wrong psychiatric diagnosis, or even that they died young or became socially marginalized or even delinquent. Helles & al. [14] consider the possible influence of comorbid disorders on an association between personality dimensions and ASDs and they insist that there have to this date been no studies examining temperament and character in relation to ASDs in combination with anxiety or mood disorders. And one last or, for a very small group, that they were able to “pass through” and manage a certain measure of social integration. But how was that accomplished?

If individuals diagnosed at a young age now receive the follow-up and support they need, there have been many other people with autism who fell through the medical-social net and were sometimes diagnosed only very late in life, well after their adolescence and into middle age, or even later. These are the people with autism spectrum whose intact cognitive capabilities enabled them to manage what we consider a praiseworthy and admirable labor of camouflage. They will have often remained in the shadows, unable to develop their full potential, and will have mixed with the general population, often without anyone knowing or even without their own knowing, despite their deeply-seated feeling of social maladjustment. A strange

feeling among many others and a painful feeling they will have believed to be completely normal, especially being unable to compare their discomfort with anything else--as what they experience is, by its own definition, rare and inexpressible. And so these individuals will have adapted as best they can, and will have sometimes succeeded in their lives despite their differences, having had the wisdom to make choices that suited them, appropriate to their skills, or having benefitted from an environment that suited them, in order to acquire new skills and succeed even more. They will have adapted in such a way as to render their difference completely acceptable, accepted and even appreciated, and eventually even undetectable. But the way the person on autism spectrum adapts is completely extraordinary as it is excessive and requires so much mental energy. Unfortunately, this over-adaptation hides without diminishing the difference in functioning, something which creates a lot of daily stress, chronic anxiety, and a mounting confusion - all of which comes from the worry of wanting to do correctly, to do well, to manage to do like others while unaware of his or her condition. And this is where a deeper difficulty will take root.

Addressing the issue when someone on autism spectrum is still young makes it possible to avoid the development of a harmful, future issues and their consequences, and also to help them find, over time, a comfortable and suitable place, their own place, in society. Addressing the issue in time should also and above all enable them to make an informed choice in terms of orienting their life with respect to their interests and needs, and even their limits, allowing them to give the best of themselves and to find fulfillment as their true selves in a way that is also unique to each individual. In this way they will contribute to the well-being of a community instead of having to be supported by that community. Because the intrinsic and specific qualities of a person on autism spectrum, just like his or her original abilities, are truly useful and productive when the person is placed in a suitable and fitting setting which takes their difference into consideration without any perception of this as a privilege. It is truly a loss for the entire society when the individual's abilities are not utilized because the autism has gone undetected. And an individual on autism spectrum runs a high risk of developing comorbidities over the long term.

It's easy to see that the initial investment in terms of early detection, eventual psychotherapeutic support, coaching or social support, but also specialized training, and all related financial costs will be less than the cost of a community bearing the costs later for the failure of a professional path that is unsuitable to the individual's actual personality and their very particular profile. Today, it is a question of common sense to care for these adults to better understand their needs in time to prevent the risk of failure in all areas of their life, because in the end autism spectrum is not an illness but a situational handicap. There isn't, however, any perspective on the effects of aging in this population because the field has not yet been researched [15].

The need to acknowledge autism in adulthood

Acknowledging autism in adulthood is important for providing support to the individual concerned but also for their family, professional and social entourage, all of whom are often tangentially impacted. Our study [16] showed that the average age at which adults were diagnosed was 34 years old. The specific needs of the person on autism spectrum, as well as their atypical functioning will have been experienced by the individual concerned beneath a veil of secrecy since nothing will have been formally recognized or diagnosed until a certain time. Until then, the individual's over-adaptation will have cost so much energy that they will increasingly struggle to find enough to continue to provide the same effort while pretending otherwise by focusing first on the satisfaction of others. This vicious cycle is so strong that the individual's quality of life will be progressively and profoundly affected, both in terms of somatic health and physical

health [17,18]. Isolated or accumulated disorders will appear around sleep, diet, various addictions and physical pains, conjugal issues if there is a couple involved, relationship-based conflicts and social reclusion to avoid those relationships, depression or burnout [19]. And it is these incomprehensible comorbidities, sometimes accumulated, which will lead the person to seek consultation. Unfortunately, an Autism's diagnosis will probably find itself hidden again beneath these more apparent problems, and even more so if the doctor isn't aware of the possibility of autism in adulthood. In the case when the doctor is a specialist in the area, the differential diagnosis should be rigorous. But many years of misdiagnoses can pass before the individual manages to find this kind of specialist. And during this time, the situation will have worsened across all areas [16]. It is both the individual and the individual's direct entourage who will have suffered an incomprehensible disconnect, even behavioral and communication problems. In this situation, the person on autism spectrum will suffer a deep loss of self-esteem which can lead in turn to a deep and lasting depression. Helles & al [20] insist that very little research is known regarding the quality of life in individuals who themselves have an ASD. Lin & Huang [21,22] show that people with an autism spectrum disorder scored significantly lower in all areas of quality of life compared to controls. Adults with an autism spectrum disorder reported a higher anxiety level, more loneliness, and the comorbid psychiatric disorders and loneliness were predictive of the social relationship domain.

The greatest difficulty for an adult with undiagnosed Autism spectrum resides in his or her lack of awareness of the permanence and the nature of the condition. Person on autism spectrum will attribute their problems and discomforts to fatigue, overwork, or their own incompetence. Or they will justify their feelings through other biases - external, contextual, caused by a third party - and will persuade themselves that the rest of the time they are fine. This means that person on autism spectrum will explain their discomfort, their pointed "disconnect", by finding reasons that hold up, even if they are false, and they will avoid the idea that this disconnect might be coming from themselves, especially since they have experienced this forever and have been accepted, for better or worse, by their entourage. They will be fatalistically obligated to consider themselves normal, and to just think they are less efficient, even less "good" than others because they must work so hard in areas where others seem to manage effortlessly, even in the social sphere where other people appear to gain energy from their feeling of belonging.

But little by little, this discomfort will become suffering, and person on autism spectrum will find themselves confronted with difficulties that create a kind of wall, a "too much", and in the best of cases they will decide themselves to seek help. We consider this a best-case scenario when considering how high the suicide rate is among person on autism spectrum. The study by Storch et al. [23] mentions that 11% of individuals with autism who were studied reported suicidal thoughts and behaviors associated with depression [15,25]. Cassidy et al. [25] discovered that people with autism presented an increased tendency for suicidal thoughts compared to a sample of the general population in the United Kingdom (the ratio reported is a 9.6 times higher risk compared to the general population). The study by Chen et al. [15], a longitudinal study conducted with a large sample size, noted a higher probability of suicide later in life with the appearance of psychiatric comorbidities.

Furthermore, for person on autism spectrum, communication difficulties and sensory particularities make romantic life less easily accessible over time compared to individuals without autism, and make difficult the social fulfillment that is so important in our western society [17]. Therefore, it is so important to understand that behind a spontaneous quest for diagnosis is almost always great suffering for the autism in adulthood.

This means that recognizing the autism in adulthood becomes an issue of humanism and fairness, beyond the first question of public health. Similar to the support provided to those with somatic health difficulties or psychological disorders, it follows that autism in adulthood must also be recognized in their difficulties, oriented or reoriented, accompanied throughout their processes, helped and supported when they no longer have the resources to confront their situation and if any associated comorbidities and accompanying suffering have taken over.

What occurs are different varieties of psychological distress, internal injuries if you like, which person on autism spectrum find strategies to avoid, strategies which are really just crutches used to remain undetected by themselves and in the eyes of others. These crutches enable them to function for a while as prescribed and compelled by our contemporary cultural and socioeconomic model. But this does not prevent them from their secret dysfunction and their silent suffering. And these internal injuries will finally trigger other psychological imbalances as a result of being compelled to secretly--and constantly and awkwardly--overcompensate and over-adapt. These individuals are going to exceed their limits, disregarding their own fundamental needs which are sometimes a little different.

It is an alarming portrait, and yet there remains--in the general population and even among medical professionals--a double refusal to accept and easily acknowledge autism in adulthood. It is often considered that if the disorder was not identified in childhood or at the latest during adolescence, and that the individual seems to have been able to lead a more or less normal life, then there really is No disorder. Unfortunately for many psychiatrist the main thrust of it - that autism in adulthood spectrum needs to be recognized. It's wrong, in your study [16] we compiled information from 91 autism in adulthood and the average age the patient was first diagnosed was 34.05 (standard deviation of ± 10.12 years divided between 19 and 73 years). This happens even more so because the autism in adulthood is neither a handicap eliciting compassion nor an extraordinary gift worthy of admiration. An emerging scientific discovery should be applied. Ignoring its brings us sadly to obscurantism.

One of the goals of this perspective is thus to affirm that autism is primarily the expression of a neurobiological diversity and richness that until now has remained largely unknown, simply because its secret, off-centered, and often solitary nature means it is rarely confronted. Whether the etiology of autism is natural, genetic, multifactorial or caused over time by the industrial environment does not change much in terms of how to deal with the individuals who live with this condition today [26]. Not recognizing this diagnosis in adults is essentially condemning them to continue their work of being sapped from within, their work of camouflage, identification, and over-adjustment, and this only perpetuates their suffering in terms of feeling untrue, that they do not belong and therefore do not exist. Worse, it condemns the individual's professional and private entourage to a blindness surrounding the individual concerned, and this blindness implicitly endorses the individual's suffering since we now know the proponents and outcomes of autism. On top of everything else, not acknowledging this diagnosis deprives these individuals and their entourage of a certain well-being and even deprives society of a healthy contribution, proportionally speaking, by the difference in point of view they would bring.

THE INVISIBILITY OF THE MASK OR THE ART OF REMAINING HIDDEN:

How is it possible that the person on autism spectrum remains invisible during childhood?

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Several hypotheses have been given by different authors [15,25,27,28]. First, autism during adolescence and in adults can be associated with mood disorders (depression and bipolar disorder). Secondly, the irritability linked to autism and the emotional instability can contribute to the risk of suicide and thus can be misdiagnosed [29-31].

The fact that adults are diagnosed relatively late should be considered the simple and clear proof that their disorder was unfortunately successful in keeping itself hidden until that point. On the contrary, doubting that autism spectrum was unperceived in childhood puts the adulthood diagnosis in question as well. The autism spectrum's invisibility is a direct consequence of the blindness and deafness of the individual's entourage. Because in order to see, one must be aware of what is being seen, and to be heard, one must connect what is being said (often a complaint) with something that is known to exist. In other words, by looking back through these adults' childhoods, there are often numerous examples of an expressed complaint and other significant events which were simply not heard nor understood at the time as an expression of autism. For each adult diagnosed late, the diagnosis is indeed a key to understanding that individual. The individual's entourage remembers all of these strange episodes but also remembers that it wasn't a big deal because the person was more or less functioning. We don't tend to worry much about a machine that is working, do we? We focus on the one that is broken. It is really unfortunate that the person on autism spectrum in adulthood come into themselves despite these dysfunctionings - all of which they are aware, and which bother them yet do not stop them from functioning.

Yes, he just needs to keep going and everything will work out, which is often what the child in this situation hears around him. Intelligent as he is, there is no reason to complain, he's just waiting to get older. And when he is older, he's become a kind of patched-together adult who can no longer go backwards to fix that loose screw.

How is it possible that autism in adulthood remains undetected within a private life?

Because a person learns quickly to hide what appears to be socially shameful, what we hide instinctively becomes very quickly shameful in our own eyes and thus remains hidden. In this way, the true personality of an adult with autism spectrum is most often hidden from others and becomes something the individual is ashamed of.

And by continuing to live this charade, the person manages to become a completely acceptable person in the eyes of others. To become a "nice person." These efforts will be rewarded and people with Asperger's will succeed in believing themselves to be who they appear to be. The fear of being discovered will be reduced when they have completely succeeded to persuade themselves that they are no longer what they were before, when they will have completely become the social mask so carefully constructed over the years. Until they have forgotten their true selves. Until the mask smashes and breaks, allowing an irritability and inflexibility to appear. So now are we dealing with Dr. Jekyll (the pleasant and acceptable part) and Mr. Hyde (the inflexible and rigid part)?

It is certainly difficult to understand what person on autism spectrum feel when they successfully give an image of themselves that is acceptable for others. The mask isn't formed to hide behind or to please others, it is probably a real survival strategy, it is an instinctive and absolute necessity because those who do not manage this find themselves stuck at the side of the road.

Nowadays, no one would dare dispute the legitimacy of these battles, right?

II. ECONOMIC AND SOCIAL RESPONSIBILITIES

It is well known that Switzerland is one of the most retrograde western countries when it comes to the diagnosis and care in the field of autism. In a government report it's mentioned that [32] :

There is a considerable delay in acquiring a diagnosis. In most cases, in Switzerland, the diagnosis is given closer to 5 or 6 years of age, compared to 18 months in the USA. There is also a lack of qualified personnel and a lack of autism-specific training. There is a lack of specialized centers for providing care for individuals with autism, especially for pre-school aged children. Also, there is no consensus on treatment. Lin insist that (Lin 2017): « Adults with autism spectrum disorder need more supportive social contexts and interventions to improve their quality of life. Social relationships, psychological health, and sensory processing difficulty must be considered when designing treatment programs for adults with autism spectrum disorder. Understanding factors associated with quality of life among adults with autism spectrum disorder can contribute to address their needs. Occupational therapy can facilitate health promotion through working with adults with autism spectrum disorder. Social relationships, psychological health, and sensory processing difficulty must be considered when designing treatment programs for adults with autism spectrum disorder ».

Longitudinal studies confirm a pessimism regarding the outcome of person on autism spectrum. Chen et al. [15] have unfortunately shown that these individuals have a higher risk of suicide attempts later in life compared to the general population. Autism was regarded as an independent risk factor after adjusting for demographic data and psychiatric comorbidities. In clinical practice, symptoms linked to suicide and psychopathology should be more carefully monitored in individuals with autism. Switzerland might have a role to play in addressing this issue. Although the medical, economic, and social challenges around autism in adulthood are numerous, the country's small size, as well as its high standard of living, Switzerland need the obligation to upgrade when it comes to the diagnosis and care in the field of autism. Maddox & Gaus [33] insist that: "In recent years in USA, it appears that community MH clinicians are increasingly recognizing autism in their undiagnosed adult clients". It is truly a general societal question, involving society's responsibilities and the issues at stake, to know how society will manage the fact that it was unable to see, or didn't want to see, something that is so obvious upon a second glance. Unfortunately, for many psychiatrists in Switzerland that the person on autism spectrum that remain undetected until middle age is largely anecdotal.

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V. CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported

REFERENCES

- [1] **DSM-V, editor. DSM-V.** Diagnostic and Statistical Manual of Mental Disorders, 5th Edition. Washington, DC: American Psychiatric Association; 2013.
- [2] **Baron-Cohen S.** Autism: the empathizing-systemizing (E-S) theory. *Ann N Y Acad Sci.* 2009;1156:68-80.
- [3] **Baron-Cohen S, Leslie AM, Frith U.** Does the autistic child have a "theory of mind"? *Cognition.* 1985;21(1):37-46.
- [4] **Lai MC, Lombardo MV, Baron-Cohen S.** Autism. *Lancet.* 2014;383(9920):896-910.
- [5] **Frith U.** Autism: Explaining the Enigma. London: Blackwell; 2003.
- [6] **Frith U, Frith CD.** Development and neurophysiology of mentalizing. *Philosophical transactions of the Royal Society of London Series B, Biological sciences.* 2003;358(1431):459-73.
- [7] **Giuliani F, D'Armi N.** Particularities of Visual Scanning in Static vs Dynamic Situations for Asperger's Subjects: New Advance in ASDs. *Austin Journal of Autism & Related Disabilities.* 2016;2(4):1028-32.
- [8] **Klin A, Lin DJ, Gorrindo P, Ramsay G, Jones W.** Two-year-olds with autism orient to non-social contingencies rather than biological motion. *Nature.* 2009;459:257-63.
- [9] **Tardif C, Laine F, Rodriguez M, Gepner B.** Slowing down presentation of facial movements and vocal sounds enhances facial expression recognition and induces facial-vocal imitation in children with autism. *Journal of Autism and Developmental Disorders.* 2007;37(8):1469-84.
- [10] **Giuliani F, El Korh P.** Psychothérapie de personnes vivant avec le syndrome Asperger autour de la caetextia. *Swiss Archives of Neurology and Psychiatry.* 2014;165(8):298-305.
- [11] **Griffin J.** Autism : a sea change. *The New Therapist.* 1999;6(4):10-6.
- [12] **Griffin J, Tyrrell I.** Parallel Processing. *Human Givens Journal.* 2008;15(4):11-7.
- [13] **Griffin J, Tyrrell I.** *Human Givens.* East Sussex: HG Publishing; 2003.
- [14] **Helles A, Wallinius M, Gillberg IC, Gillberg C, Billstedt E.** Asperger syndrome in childhood - personality dimensions in adult life: temperament, character and outcome trajectories. *BJPsych Open.* 2016;2(3):210-6.
- [15] **Chen MH, Pan TL, Lan WH, Hsu JW, Huang KL, Su TP, et al.** Risk of Suicide Attempts Among Adolescents and Young Adults With Autism Spectrum Disorder: A Nationwide Longitudinal Follow-Up Study. *J Clin Psychiatry.* 2017;78(9):e1174-e9.
- [16] **Giuliani F, El Korh P.** Adult with Autistic Spectrum Disorders: Specialized Treatment. *Advanced Techniques in Biology & Medicine.* 2016;4(1):164-8.
- [17] **Giuliani F, El Korh P.** Profils des patients suivis dans une unité spécialisée Asperger. *Swiss Archives of Neurology and Psychiatry.* 2016;167(3):88-93.
- [18] **Giuliani F, El Korh P.** Troubles du spectre de l'autisme: stratégies compensatoires. *Swiss Archives of Neurology and Psychiatry.* 2016;167(4):125-9.
- [19] **Pallathra AA, Calkins ME, Parish-Morris J, Maddox BB, Perez LS, Miller J, et al.** Defining behavioral components of social functioning in adults with autism spectrum disorder as targets for treatment. *Autism research : official journal of the International Society for Autism Research.* 2018;11(3):488-502.
- [20] **Helles A, Gillberg IC, Gillberg C, Billstedt E.** Asperger syndrome in males over two decades: Quality of life in relation to diagnostic stability and psychiatric comorbidity. *Autism : the international journal of research and practice.* 2017;21(4):458-69.
- [21] **Lin LY.** Quality of life of Taiwanese adults with autism spectrum disorder. *PLoS one.* 2014;9(10):e109567.
- [22] **Lin LY, Huang PC.** Quality of life and its related factors for adults with autism spectrum disorder. *Disabil Rehabil.* 2017:1-8.
- [23] **Storch EA, Sulkowski ML, Nadeau J, Lewin AB, Arnold EB, Mutch PJ, et al.** The phenomenology and clinical correlates of suicidal thoughts and behaviors in youth with autism spectrum disorders. *J Autism Dev Disord.* 2013;43(10):2450-9.
- [24] **Takara K, Kondo T.** Comorbid atypical autistic traits as a potential risk factor for suicide attempts among adult depressed patients: a case-control study. *Ann Gen Psychiatry.* 2014;13(1):33.
- [25] **Cassidy S, Bradley P, Robinson J, Allison C, McHugh M, Baron-Cohen S.** Suicidal ideation and suicide plans or attempts in adults with Asperger's syndrome attending a specialist diagnostic clinic: a clinical cohort study. *Lancet Psychiatry.* 2014;1(2):142-7.
- [26] **Ansermet F, Giacobino A.** *Autisme: à chacun son génome.* Paris: Navarin - le champ freudien; 2012.
- [27] **Richa S, Fahed M, Khoury E, Mishara B.** Suicide in autism spectrum disorders. *Arch Suicide Res.* 2014;18(4):327-39.
- [28] **Selten JP, Lundberg M, Rai D, Magnusson C.** Risks for nonaffective psychotic disorder and bipolar disorder in young people with autism spectrum disorder: a population-based study. *JAMA Psychiatry.* 2015;72(5):483-9.
- [29] **Mazefsky CA, Herrington J, Siegel M, Scarpa A, Maddox BB, Scahill L, et al.** The role of emotion regulation in autism spectrum disorder. *Journal of the American Academy of Child and Adolescent Psychiatry.* 2013;52(7):679-88.

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- [30] **Samson AC, Hardan AY, Lee IA, Phillips JM, Gross JJ.** Maladaptive Behavior in Autism Spectrum Disorder: The Role of Emotion Experience and Emotion Regulation. *J Autism Dev Disord.* 2015;45(11):3424-32.
- [31] **Samson AC, Phillips JM, Parker KJ, Shah S, Gross JJ, Hardan AY.** Emotion dysregulation and the core features of autism spectrum disorder. *J Autism Dev Disord.* 2014;44(7):1766-72.
- [32] **Golaz F.** **Spectre autistique : importance d'un diagnostic et d'une prise en charge précoces et d'une pluralité des approches thérapeuthiques.** In: d'Etat C, editor. Lausanne2013.
- [33] **Maddox BB, Gaus V.** Community Mental Health Services for Autistic Adults: Good News and Bad News. *Autism in Adulthood.* 2018;1(1).

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