Association des parents d'enfants Asperger

Redefining Autism for the DSM[1, 2]

(to include Aspie Syndrome)

October 24, 2021

[1] In replacement of the current text on ASD in DSM-5 manual (p. 50 to 59).

[2] To access the rationale behind this proposal, please consult the full text of two Position Papers on this issue previously submitted to the APA (as of November, 2019 and july, 2020). They are available upon request from Jacques Lafortune at jlafortune63@hotmail.com.

In short: a reminder of the key elements of our analysis

In our two previous Position Papers submitted to the APA, for the return of Asperger's syndrome in the DSM, we essentially:

- Demonstrated the neuro-anatomical, clinical and sociological foundations of Asperger's syndrome;
- Carried out a thorough review of the scientific literature that supports the differentiation of "high-level autism" and "Asperger's syndrome", even though the conditions are similar;
- Asserted that the new Autism Spectrum Disorder construct (ASD) introduced by the DSM-5 does not have the homogeneity required for an unambiguous designation;
- Stated that the notion of an Autism Spectrum is at best analogous, at worst misleading;
- Claimed that the resulting 39-word definition of autism in the DSM-5 is confusing; by making it longer, the definition becomes more hermetic than clear;
- Evoked an obvious fact: the condition known as Kanner with ID (intellectual disability), in other words, classical autism is not spectral but monolithic;
- Recalled that mild, atypical autism, previously called Asperger's syndrome[3], has been slipping into oblivion since 2013 and is lodged in the blind spot of medicine; at the same time, differential diagnoses began proliferating, without an integrative vision of symptoms;
- Brought up a major oversight: the principle that the simplest assumptions should prevail in explaining psychological conditions (Ockham's razor principle) is not present. This does not allow for a clear and unambiguous diagnosis;
- Asserted that there is a strong factor of differentiation between the profiles of spectral autism: this factor is the degree of anosognosia and thus of insight. This insight and its effects emerge "developmentally". This condition is therefore evolutionary: early in Asperger's syndrome, late and partial in high functioning autism. The acquisition of insight is a long process. In the Asperger child, there is no insight as this element emerges around the age of 12 in girls and 16 -18 in boys;
- Recalled that the person with Asperger's syndrome is a sort of impaired neurotypical person and a failed autistic person (“an unfinished autism condition” (Attwood);
- Agreed that the Asperger profile is the terminal stage of the autism spectrum, an atypical form of autism;
- Said that we must hear the suffering of Asperger adults who seek a bit of light and oxygen regarding the possible presence in them of such a mitigated form of autism;

[3] The condition should have been named Soukhareva’s Syndrome since it was firstly described and pinpointed by this Russian psychiatrist in an 1926 article.

- Affirmed that the quest for identity, in the person with Asperger's Syndrome, often pursued for years, marked by torment, results in a convenient and precarious avatar in a world where it is imperious to adapt;
- Concluded to another obvious fact: Asperger's autism is the most prevalent and diverse form of the condition. High Functioning Autism (HFA) is rarer, and Classical Autism, even rarer than this one;
- Stated that Asperger's symptoms (the configuration of comorbidities) are *à la carte*; social interaction is the predominant source of disability;
- Evoked the wheel of contributing dimensions as per Figure 1 below, without forming of categories, due to the fact that the algorithms likely to delineate those categories are not known. An attempt to psychometrize such algorithms is proposed by ADOS-2; it will be necessary to continue the process, differentiating the groupings for each profile; and
- Recognized that the notion of the autism spectrum was introduced in the DSM-5 without the necessary validations for a range of multiple autistic conditions, for all ages and for both sexes.

Fig 1 Autism contributing dimensions, without categories (as reproduced from article by Rosen, Lord, & Volkmar, 2021[4])

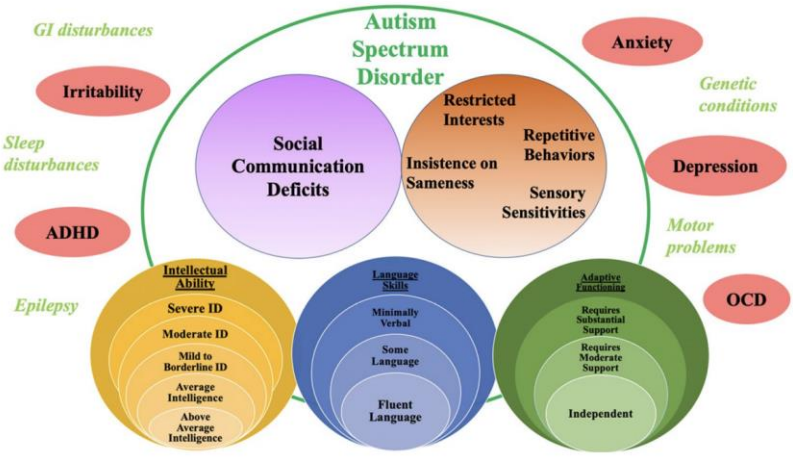


Fig. 1 Overlap between categories and dimensions for core ASD symptoms and non-ASD symptom specifiers

Springer

[4] Rosen, N, Lord, C, Volkmar, F. (2021). *The diagnosis of Autism: From Kanner to DSM-III to DSM-5 and Beyond*. Springer. On line.

NEW DEFINITION OF AUTISM

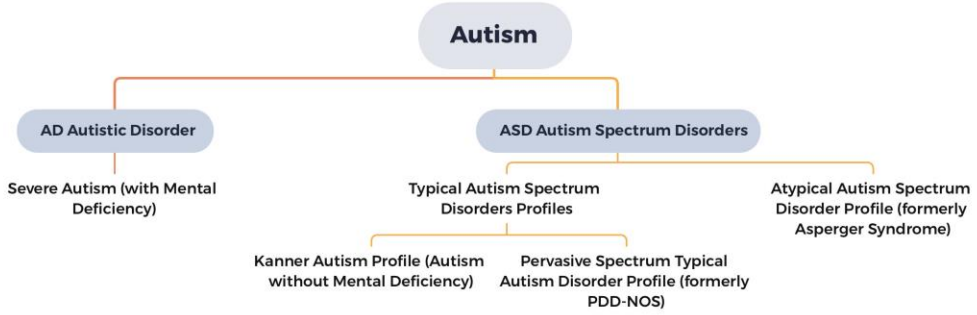
A new definition of autism, comprising of both the known dimensions (see figure 1) and the categories (algorithms' definitions, yet to be established-being a work in progress), is needed. Basically, this new definition should stipulate that:

Autism manifests itself in two forms: *Autistic Disorder (AD) and Autism Spectrum Disorders (ASD);*

ASD itself is manifested in two forms[5]: *Typical Autism Spectrum Disorders and Atypical Autism Spectrum Disorder (Aspie Syndrome).*

The following diagram illustrates the new concepts
(Geraldine Westerkamp (westerdine@gmail.com, 2021**).**

Fig 2 Autism Profiles, Without Contributing Dimensions



[5] This dichotomous nomenclature is consistent with Baron-Cohen's concerns expressed in his 2018 article (*American Scientific*): "Is It time to Give Up on a Single Diagnostic Label for Autism?" https://blogs.scientificamerican.com/observations/is-it-time-to-give-up-on-a-single-diagnostic-label-for-autism/

Rationale for Change

Unexpected consequence of DSM-5 labelling choices: the narrowing of the Spectrum

In 1994, Asperger's syndrome (AS) was introduced in the DSM-IV as a separate condition of autism and in 2013 it was removed as such. Reason: the concept was considered imprecise, the condition difficult to diagnose. A generic name called "Autism Spectrum Disorder (ASD)" brought together and replaced the traditional sub-categories of autism. After eight years of experience, what have been the effects of this merger and the consequences of the withdrawal of the Asperger designation?

In appearance, the concept of "spectrum" would bring useful and practical flexibility to the work of clinicians. In particular, it was to allow for the shift of individuals within the newly created homogeneous mega-category, in the event of symptomatic changes, as discussed by Baron-Cohen[6].

However, this advantage soon proved spurious. The vagueness of the generic name ASD which was created led to a narrowing of the spectrum in the minds of clinicians. At one end, integral autism with intellectual deficiency stands ignored because too different. At the other end, mild autism, latent, with little or few specific identifiers, relegated to differential diagnoses. In the middle of these extremities, the autism spectrum, the mirage of neurodiversity.

The ASD designation is now at risk of not serving anyone affected by the condition (Alison Singer, keynote speech, INSAR 2017; quoted by Baron-Cohen. Indeed, the most affected condition (with intellectual disability) and the least affected (Asperger's) both suffered this narrowing of the choice made by clinicians towards the middle of the spectrum, a sort of double regression.

The insidious impact of the change brought about by DSM-5 must be indeed fully understood. The absence of clear delineations of this spectrum, of its scope, of its finite or less-defined forms, had an unexpected effect: narrowing the scope of the spectrum. Diagnoses are thus made towards explicit forms of autism rather than implicit and veiled forms, in particular Asperger's syndrome. Clinicians no longer venture to the end of the spectrum, into the ambiguous zone of the Asperger condition.

In the absence of such a multiple-nosological category, their reflex is to either assert to an unequivocal, visible and obvious autism, or fall back, in a conservative fashion, on differential diagnoses such as ADHD (in children), BPD (in women) and Mood Disorder (in men). Or on other diagnoses such as anxiety disorder,

[6] Baron-Cohen, S. (2018). Is It Time to Give Up on a Single Diagnostic Label for Autism? In *American Scientific.* https://blogs.scientificamerican.com/observations/is-it-time-to-give-up-on-a-single-diagnostic-label-for-autism/

adjustment disorder, OCD disorder, etc., all sources of diagnostic myopia and clinical mystification. The number of differential diagnoses has suddenly increased: in fact, it proliferates because of the continuous adding of new labels to cover symptoms which keep expanding.

This is the opposite of the principle of parsimony[7]. Thus, the specific particularities of the person with atypical autism, that is to say with mild and insidious autism, like Asperger's autism, are no longer placed in the right perspective. Indeed, the symptoms revealing Asperger with their relative multiplicity, disparity and limited severity - in short, the clinical array - continue to have an integrative value, under that label, greater than the simple accumulation of reductive differential diagnoses.

Other consequence: **the sociological impact**

What about the impact of the AS removal (from the DSM-5) on the Asperger community, on the many national and local Asperger communities and support groups? It is a painful, misunderstood loss. Their suffering is further increased by the professional community which is now turning its back on them. And what of Asperger children who are readily placed in classes of deficient or rebellious children, failing to recognize the "specificity" of their condition, as Temple Grandin reported to us. However, there is no common measure between a child with Asperger's and a child with autism, even of presumed normal intelligence (Attwood). It is only after years of learning, acculturation, and development that they will come together, relatively.

Let us put the nosology of autism in order. Let us give legitimacy to the extreme forms of autism, notably a recognition of both the unequivocal autistic disorder and the Aspie condition.

Autistic Disorder (AD)

This condition is characterized by a mix of intellectual deficiency and autism. Interaction between the two conditions is the dominant feature, resulting in a complex idiosyncratic developmental disorder. There is no continuum of the condition, no spectral handicap. Intellectual disability is essentially revealed by an IQ below 70, often not measurable, and other features related to learning and adaptation capacity. Pervasive severe autism is the formal cause of the disorder. It appears as a radical alteration of social communication and social interaction capacities, resulting in an extreme lack of autonomy and social integration capability. Insight does not exist or is very limited. Acquisition of language is often an issue. Alternative communication systems are introduced early in life. Paradoxically, savant syndrome may sometimes be present.

[7] Called Ockham's Razor Principle: Principle of simplicity, parsimony, rationality: multiples should not be used without necessity, the simplest hypotheses should be privileged.

Core Diagnostic Criteria

The formulation of diagnostic criteria for this condition dominated by severe autism and intellectual disability is a separate challenge not undertaken in the present proposition as focusing on Aspie condition. The definition of it would advantageously be inspired by the chapters devoted to this condition in the new encyclopedia of the *American Psychological Association*, as described in the 32nd publication of the *APA Handbooks in Psychology*[8] series.

Severity levels: 2 ("requiring substantial support") or 3 ("requiring very substantial support". See, DSM-5, p. 52).

[8] American Psychological Association (2020). *Handbook of Intellectual and Developmental Disabilities.* 2 volumes, APA Publishers, Washington DC.

Autism Spectrum Disorders (ASD)

ASD is at best roughly spectral, more by analogy than graduated as in a true spectrum (of colors, for example). Indeed, it varies in degrees. It is a coarse range with approximate gradients. The range is broken into three profiles linked to an array of comorbidities. The common trait: intelligence is normal. The profiles are:

- typical classical, quasi-integral autism
- typical pervasive partial autism (including the condition formerly called PDD-NOS)
- atypical autism - Asperger's Syndrome (Aspie)

The autism spectrum is spread over an irregular continuum, with varying degrees and multiple overall forms brought about by the specific comorbidities of each individual and by the global "degree" of autism.

Transition between the three profiles happens over life span. Surprisingly, any spectrum condition is an evolving condition; insight develops, slowly, as a work in progress. Combined maturation and learning progressively weaken the spectral presence of autism. As a consequence, transition from one profile to the next is expected when support and continuous learning are insured. Evolution moves towards the end of the spectrum which itself borders normality.

Two types of individuals with ASD are identified. First, typical classical quasi-integral autism, and second, those who carry an untypical condition.

This second condition is newly called **Aspie Syndrome**[9]. In both cases, intelligence is normal, average or superior. The first and the second group individuals are ultimately differentiated on the basis of their degrees of autism as associated with varying levels of acquired insight. Autism is predominant in the first condition until adulthood, revealing a limited degree of normality. In Aspie Syndrome, the personality is predominantly neurotypical, with some residual autism; insight arises during adolescence.

Global diagnostic and Associated Features Supporting Diagnosis of ASD

A description of common features of ASD, both typical and atypical, is to be updated from actual text in DSM-5 pp. 53-55 and current literature, since 2012. Core diagnostic criteria follow for each condition.

[9] Or "Aspie Profile", for the Community.

First Sub-Group of ASD (children, adolescents, and adults)

Typical Autism Spectrum Disorders

Core Diagnostic Criteria[10]:

A. Persistent and pervasive deficits in social communication and social interaction across multiple contexts.
B. Restrictive, repetitive patterns of behavior, interests, or activities.
C. Symptoms must be present in the early developmental period.
D. Symptoms cause clinically significant impairment in social, occupational, or other areas of current functioning.
E. These disturbances are not explained by intellectual disability.
F. The child/adolescent/adult may have splinter skills (or exceptionally, savant syndrome).
G. Insight of the condition is limited and doesn't emerge, unless with outside support, before late adolescence or adult life. Limited insight is linked to marked degree of mindblindness, weak central coherence, and executive dysfunction; significant interaction between these three core factors MB/WCC/ED is expected[11].

Severity levels: 1 (requiring support) or 2 (requiring substantial support[12]).

[10] A, B, C, D, E: As stated in actual DSM-5 text, p.50. However, a reordering and an update of these statements which date from 2012 are desirable in light of the American Psychological Association's (2020) *APA Handbook of Intellectual and Developmental disabilities, vol. 1,* pp. 207-212, formulations.

[11] See an analysis of this phenomenon for medical students in Giroux, M., & Pélissier-Simard, L. (2021). *Shedding light on autistic traits in struggling learners: A blind spot in medical education.* Perspective on Medical Education. Springer Link. https://link.springer.com/article/10.1007/s40037-021-00654-z

[12] As stated in Table 2 of actual DSM-5 official text, page 53.

Second Sub-Group of ASD (children, adolescents, and adults)

Atypical Autism Spectrum Disorder (Aspie Syndrome)

Core Diagnostic Criteria[13]:

A. Persistent deficits in social communication and social interaction across multiple contexts.
B. Restrictive, repetitive patterns of behavior, interests, or activities.
C. Symptoms must be present in the early developmental period.
D. Symptoms cause clinically significant impairment in social, occupational, or other areas of current functioning.
E. These disturbances are not explained by intellectual disability.
F. The child/adolescent/adult may have splinter skills.
G. Neurotypicality is a dominant feature though not exclusive, since mixed with autism singularities; Insight of the condition is evolving starting from adolescence into adult life.
H. Insight of the condition is clearly emerging in adult life. Insight is appreciated by moderate degrees of mindblindness, and/or weak central coherence, and/or executive dysfunction; and light or partial interaction between these three core factors MB/WCC/ED.

Severity Level: 1 (requiring support)[14].

Additional diagnostic features for Aspie syndrome

1. Against a background of prevalent neurotypicality, the child, the adolescent or the adult presents multiple, disparate, age-related atypia and comorbidities such as ADHD, food selectivity, sleep disorders, eye contact disorder, anxiety disorders, mood disorders (including anger and tantrums), affect disorders (flat or exalted affect), etc.
2. Other comorbidities have also been observed in children: impaired executive efficiency, loss of autonomy, oppositional disorders, ruminations, obsessive-compulsive disorders, hording disorders, bipolar disorders, gender dysphoria, tics, pica, mannerisms, stereotypies and repetitive behaviors including trichotillomania, phobias, misophonia, rigidities, self-stimulation, self-mutilation, oral communication disorders (absence or limitation of language, selective mutism) including echolalia, expressive and receptive language disorders, sensory defenses (hyperesthesia) and conversely hypo-sensitivity, relational and socialization disorders, fine and

[13] A, B, C, D, E: As stated in actual DSM-5 text, p.50. However, a reordering and an update of these statements which date from 2012 are desirable in context with the American Psychological Association's (2020) *APA Handbook of Intellectual and Developmental disabilities, vol. 1,* pp. 207-212 formulations.
[14] As stated in Table 2 in actual DSM-5 official text, page 53.

gross motor skills disorders, writing disorders (and other learning disabilities), reactive disorders of attachment, prosopagnosia disorders (face recognition), episodes of depersonalization, derealization, hallucinations, delusions, etc.

3. Developing aseity is the life goal of persons with Aspie syndrome: in a word, to be free, to be happy. These persons, immersed as they are in the neurotypical world, desperately seek to maintain their integrity, always under tension, their adaptation and their efficiency, equally being challenged. They seek to understand and to assume themselves. They seek to optimize their aseity and to conquer their equilibrium. Partial autism, with which they live, catalyzes their fundamental normality, fertilizes it, generating a force of fragile progression which is to be harnessed. An Asperger aseity exists for each person affected; it is to achieve a relative balance between the demands of both the autistic condition itself and of the environment. This integrity is achieved when spectral autism and its comorbidities are sufficiently weakened, partially neutralized, by maturation and learning in those who will, nevertheless, remain "giants with feet of clay".
4. Adults with Aspie Syndrome (male or female), when looking for diagnostic, can compose without help an explicit and elaborated written or verbal account of the difficulties experienced and of his or her quest for identity and better mental health[15]. An evocation of his or her atypical childhood is required. A lasting narrowing of the relationship gap will have hindered the acquisition of social relations. An anecdotical demonstration of his or her insight of the condition confirms the ongoing decrease of autistic anosognosia, such phenomenon being apparent in females from adolescence on, but later in boys.
5. The adult Aspie woman may have androgynous features and appear eccentric. She is seen as cold and self-centered. She has little interest in makeup, hairdressing or shopping. She doesn't like to be touched. She may have an interest in science, computer sciences design, writing, languages, psychology. She has often been diagnosed with BPD (Borderline Personality Disorder). She cultivates only one or two friendships. She gives herself exhausting neurotypical roles; she is good at disguising herself as a neurotypical person (*camouflage* syndrome[16]); she comes out of hiding only when she gives birth to a child on the spectrum.
6. Differences between Aspie syndrome and high-functioning typical autism disorders are rather quantitative (same spectrum, different degrees of it) rather

[15] Examples of such personal accounts appear in T. Powell's excellent book: Recognizing Autism and Asperger's Syndrome, 2nd ed., Routledge (2021). *Kate's story*: *Diagnosis stabilized my mental health; Joanna's story: Drafting a map to chart my course; David's Story: everything is different but nothing has changed; Rachel's Story: Diagnosis has been a gift; Floyd's Story: My role models are James Bond and Bertie Wooster; Melanie's Story: It Validated Me: I'm more autistic militant now; Gerry's story: I still feel angry … I'll never catch up; Max's Story: I was a hermit… now I try and live in the real world; Julia's story: "If I had known earlier, I might have saved my job".*

[16] As measured, for example, by the CAT-Q (Camouflaging Autistic Traits Questionnaire). https://embrace-autism.com/cat-q/

than qualitative (different syndromes) after growth years. They are distinctly more pronounced at younger ages. By late adolescence, differences are no longer obvious except for insight capacity and varying configuration of MB/WCC/ED. Indeed, this difference continues to exist, but it is more subtle and is related to the level of comprehension and intuition of self-difference, as acquired by the individual. It appears that :

1. Aspie subjects have earlier language development.
2. Aspie children also display more imitative social play and reciprocal social interactions.
3. By adolescence, Aspie subjects still show more sophisticated vocabulary and greater desire for friendship.
4. Cognitively, as a group, Aspie subjects typically show superior verbal performance and visual-spatial, perceptual and motor deficits while the opposite profile characterizes typical autism.
5. Studies that look at theory of mind performance found mainly quantitative differences typical autistics et Aspie subjects.
6. Aspie subjects show more intense preoccupations and circumscribed interests while individuals with typical autism who have poorer imaginative play and more stereotyped behaviors.
7. In terms of global functioning, AS subjects fare significantly better academically but not in terms of employment or independent living.
8. Changes occur over the years and a child who was appropriately diagnosed with Kanner's Autism can grow into an adolescent who fits Asperger's descriptions. As mentioned earlier, one thing clearly differentiates them throughout their life courses: it is insight. When insight occurs, a migration takes place on the simili-spectrum from marked quasi-integral autism to residual autism, to Asperger's, and adaptation becomes better. If the comorbidities are kept in check, through the strategic interplay of accommodation measures, the Aspie aseity becomes optimal, close to – but not reaching – neurotypical aseity.

Functional Consequences of ASD, Recording Procedures, Specifiers, Prevalence, Development and Course, Risk and Prognostic Factors, Culture-Related Diagnostic Issues, Gender-Related Diagnostic Issues, Differential Diagnosis.

These aspects are to be re-worded and adapted from actual DSM-5 text, p. 55-59. In addition, since the DSM-5 text on the above-mentioned topics was published 9 years ago, it requires a formal update. We recommend the use of Chapters 9 (Volume 1) and 6 (Volume 2) of the *APA Handbook of Intellectual and Developmental Disabilities* (2020)[17] in the formulation of the DSM-5 update.

[17] As an example of the need for an update to this suite of characteristics, we quote here the chapter on "Prevalence". In the DSM-5, it is stated that "reported frequencies for ASD across U.S. and non-U.S. countries (that) have approached 1% of the population, with similar estimates in child and adult samples" (p. 55). On the other hand, in Chapter 9 of the *Encyclopedia of the American Psychological Association* (2020, p.219), it is stated that "The CDC currently estimates that 1 in 59 children in the United States have ASD".