

MEDIATIZING ADULT AUTISM: A STEP TOWARDS BETTER UNDERSTANDING AND SOCIAL INCLUSION

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Abstract: The initial documentation of autism occurred in children, with Kanner identifying 11 cases in 1943. However, specialists acknowledge that autism has always existed, even if unrecognized before the 20th century. In Algeria, interest in autism has surged over the past fifteen years. While the diagnosis of autism in children is generally well-established, particularly for typical forms, adults are rarely diagnosed in general psychiatry, despite an estimated 1% prevalence in the overall population. This under diagnosis raises questions about the visibility of autistic adults, who also suffer from a lack of media representation. Autism can have varied outcomes in adulthood: some individuals integrate into society with ongoing social difficulties, others show partial improvement but still depend on family support, and severe cases involve significant mental retardation and behavioural challenges. Enhancing the training of general psychiatrists will improve the diagnosis and care of autistic adults.

Keywords: Autism in Adults; Evolution; Diagnosis; Socio-Professional Integration; Media

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I- Introduction :

Autism as an entity was initially described in children in a population recruited from an orphanage in the USA. Leo Kanner described it in 11 children and Hans Asperger in 4 children. (Murad.A& All, 2014, pp 577-586) The improvement of knowledge in this field, in particular on autism without mental retardation, has led to diagnosing adults who had never received this diagnosis in childhood or adolescence. (Barthélémy & Bonnet, 2012, p 45) But, if the entire scientific community currently admits that this disorder exists in adults (and we can speak of an epidemic in the epidemiological sense), it is also reported that it is difficult to diagnose and understand and that it is often poorly managed because of this. Diagnosis is even more difficult in adult women, particularly because of their capacity to partially compensate for the deficit in social interaction. An important societal issue has been revealed in recent years through sometimes quarrelsome requests from adults who define themselves, experience themselves as autistic, and wish to influence the context to be recognized as such, and accepted. Sometimes they consider autism as a particular form of intelligence, or even a superior form of intelligence, confused with high potential. In Algeria, the great interest in this disorder is relatively recent, dating back about fifteen years. Currently, the diagnosis is generally well-made in children, particularly when it is a typical form. In adults, the diagnosis is rarely made in patients encountered in general psychiatry. However, we know that there are hundreds of thousands of autistic adults, with the prevalence of autism in the general population being estimated at 1% on average. So we asked ourselves this question: where are the autistic adults? To highlight the under diagnosis of this disorder in this age group. In addition, it is important to note that there is no media promotion for this marginalized category of patients.

To answer this question, we will focus on the evolution of autism from childhood to adulthood. Overall, we could describe three modes of evolution based on several factors: a favourable evolution that gives autistic adults relatively integrated into society with the persistence of some difficulties in social interaction often tolerated by the social environment. This scenario is often observed in society.

An evolution towards a partial improvement of the disorders but with a dependence on the family and relapses in moments of anxiety. These cases can be encountered in general psychiatry consultations but are often diagnosed for other disorders such as pathological personality anxiety or depressive disorders.

Finally, an unfavourable evolution. In the latter case, autistic adults present severe mental retardation with behavioural disorders that are difficult to manage; They live with their parents who knock on every door to find ways to stabilize them at least for a certain period.

1. Autism in Algeria:

We deal much more with autistic children who are now fairly well-diagnosed.

In outpatient consultations, we find a few cases of autistic adults (aged over 18) who were previously followed up, from their childhood or adolescence.

We receive very few cases of adults referred by colleagues in general psychiatry, for suspicion of autism or management of diagnosed cases.

If we accept that the prevalence of autism is currently estimated at 1% of the general adult population, (Barthélémy & Bonnet, 2012, p 60) there would be approximately 250,000 autistic adults in Algeria. (Ould Taleb, 2006, p162)

2. Late or missing diagnosis:

Diagnostic is a common problem because many autistic adults did not receive a formal diagnosis in their childhood. As a result, these individuals may find themselves unable to access specialized health or education services. This situation is compounded by stereotypes and the prevalence of under diagnosis.

Inadequate transition services between child and adult care, limited resources, and the lack of adult-friendly services contribute to the challenges faced by autistic adults. Due to the stigma associated with neurodevelopmental disorders, these individuals may experience social exclusion and isolation, compounded by inadequate support policies.

The involvement of families and caregivers is important, as many autistic adults rely on their families for daily assistance, which reduces their visibility within public systems. This situation raises a nuanced and complex discussion about care for autistic people, particularly during their transition to adulthood.

Faced with these challenges, we have reason to ask the following questions:

- Where are these hundreds of thousands of autistic patients in Algeria as adults? Why do they not appear in the health or socio-educational fields of the country?

3– Objectives: The objective of this work is twofold:

Raising awareness among professionals about adult autism:

- a. Better detection: Signs of autism in adults may be less obvious than in children, as they may have developed compensatory mechanisms. Specific training allows health professionals to better recognize these signs, thus improving diagnosis.
- b. Adaptive care: Autistic adults have different needs than children. Increased professional awareness can improve patient's quality of life by providing more personalized and adaptable care.
- c. Reducing inequalities: By raising awareness among professionals, we reduce disparities in access to care for autistic adults, thus promoting a more equitable and inclusive approach.
- d. Continuing education: Professionals must keep up to date with the latest research and technologies on autism to provide quality care.

Raising awareness among public authorities and parents on the importance of caring for this age group:

- a. Integration into public policies: Integrating adult autism into public policies ensures that adequate resources, including specific programs and funding, are allocated to support them.
- b. Family support: Parents play a vital role in the lives of autistic adults. By raising awareness, we strengthen family support networks by providing them with the tools and information they need to better understand and support their loved ones.
- c. Developing specialized services: Increasing awareness can lead to specialized services for autistic adults, such as day centers, vocational training programs, and employment support services.
- d. Strategic planning: By understanding the specific needs of autistic adults, governments can develop more effective and inclusive strategies to meet these needs, thereby improving social cohesion.

Raising awareness among professionals, governments, and parents is crucial to improving the screening, care, and support of autistic adults. This will lead to better social integration, a better quality of life, and a reduction in inequalities.

II- Autism in Adults:

1. Number of Studies: are rare in this field;

- A study conducted in 2012 by MUKAETOVA et al. sought the number of publications in the field of autism between 1946 and 2011 according to the age of the population studied. (Figure 1)

Table (1) : The number of publications on Autism Spectrum Disorder (ASD) by Age group.

Age Group	Number of Pub
Children	~15,000
Adolescents	~7,000
Adults	~3,000
Older People	~500
Total age spectrum	~25,500

The source : Mukaetova, Perry, Baron et al., 2012 - Geriatric Psychiatry

It can be seen that the adult population has benefited from the lowest number of studies compared to the child and adolescent populations.

The bar chart displays the distribution of publications related to Autism Spectrum Disorder (ASD) across different age groups. The search was conducted in PubMed for literature published between 1946 and January 2011 using keywords like “autism,” “autistic,” “autistic disorder,” “autistic symptoms,” “autism spectrum disorders,” “Asperger syndrome,” and “developmental disorders.” The search also incorporated terms like “children,” “adolescents,” “young adults,” “adults,” “elderly,” “aged,” and “60 and over.” The results are categorized into four groups:

Total Age Spectrum: The highest number of publications (~25,500).

Children: The second-highest number of publications (~15,000).

Adolescents: Moderate number of publications (~7,000).

Adults: Fewer publications (~3,000).

Older People: Minimal publications (~500).

Note: The "Adult" category includes both young and mature adults but excludes older adults. The results highlight a research focus on children, with limited studies on adults and older populations.

2. Warning Signs: When the diagnosis of Pervasive Developmental Disorder (PDD) has not yet been made, a certain number of signs should alert the professional to the possibility of PDD. The French High Authority for Health (HAS) distinguishes three different circumstances:

- People housed in an institution or monitored by specialized services;
- People with ASD who have a social and professional life;
- People who remain with their family.

In people housed in an institution:

inability to follow common discipline;

misunderstanding of the rules;

bizarre attitudes or surprising rituals in the acts of daily life;

unusual response (lack of reaction or paradoxical effects) to psychotropic drugs;

dismay of support staff (and families) faced with the behavior of a resident that thwarts the usual educational responses.

In people with a social and professional life:

The warning signs are mainly manifested in the area of social interactions:

recourse to university medicine or occupational medicine for misunderstandings of relationships and social codes;

frequency of impressions, experiences, and realities of harassment;

difficulties in the mode of emotional or sexual contact;

incomprehension of humor;

social withdrawal that becomes incompatible with maintaining a job, while the subject would be intellectually capable of it.

People who stay in their family:

These are the most difficult to spot because of the family's tolerance of the disorders presented by the autistic adult, in particular when there are no major behavioral disorders:

The warning signs testify to:

- difficulties in exchanging and understanding the behaviors observed, and
- the frequency of interpretations that do not take sufficient account of autistic functioning.

- However, families have generally adapted and they agree to live at the pace imposed by autistic functioning. (HAS, 2011, p 20) This can delay diagnosis and care.

3. Diagnostic approach and assessment of functioning in adults:

-An interdisciplinary clinical approach,

-Standardized tools to support the practitioners' approach.

-This approach can be interviewing, observing, and/or informing by a third party;

-The clinical approach is oriented as much towards the identification of specific autistic disorders as towards the assessment of overall functioning;

-This approach is partly dependent on the level of cognitive competence and the socio-adaptive possibilities of the person. (HAS, 2011 p 7-8)

-The scales and questionnaires recommended by the HAS: are ADOS-2, RAADS-R (Ritvo's Autism and Asperger's Diagnostic Scale - revised) and the Vineland (CRAIF, 2020).

We also know the interest of the TTAP (Transition to Adulthood Assessment Profile – TEACCH) which is the update of the AAPEP in the functional assessment of autism in adults and adolescents.

4. Transition to adulthood:

Studies on the evolution of autistic signs from childhood to adulthood have demonstrated an overall improvement in the signs (Barthélémy & Bonnet, 2012, p 50-57)

According to the French HAS guide (2011):

Nonverbal communication and language can improve throughout the entire life trajectory;

Repetitive and stereotypical behaviors can decrease in adulthood, but not very significantly;

Social interaction disorders are the most persistent element of the autistic triad throughout life. (HAS, 2011 p 7-8).

The diagnosis is still valid in adulthood but there is a great variability of symptoms according to the subjects apart from the disorders of social interactions (Barthélémy & Bonnet, 2012, p 50-57).

But the DSM-5 admits that in some cases autism does not meet all the criteria in the adult state.

This is why it introduced the sentence: "... either during the current period or in the antecedents..." when it spoke of clinical criteria A and B (APA, DSM-5, 2013, p 55-56)

The evolution of autism symptoms from childhood to adulthood is very variable and influenced by several factors:

The most frequently cited factors are:

IQ: this is the most recognized factor. When it is high, it reduces the influence of autism on adult life. (HAS, 2011 p 7-8).

a. The appearance of language before the age of 5 is cited in many studies as a good prognostic factor. (Barthélémy & Bonnet, 2012, p 50-57)

b. The appearance of epilepsy before the age of 5 is also cited as a factor that can hinder social interaction and communication (Barthélémy & Bonnet, 2012, p 50-57)

c. The existence of a medical comorbidity such as fragile X syndrome, Bournonville's tuberous sclerosis, etc. has also been incriminated among the poor prognostic factors, but this factor seems to be linked to low IQ. (Barthélémy & Bonnet, 2012, p 50-57)

Among the environmental factors, only the early treatment seems to have enough evidence of positive influence on the symptoms of autism. (HAS, 2011 p 7-8).

Other factors have been cited but with less evidence:

- The early onset of disorders;
- The intensity of the symptomatology;
- The degree of environmental support. (HAS, 2011 p 7-8).

5. Comorbidities:

Psychiatric comorbidities: It is rare for an ASD to develop in isolation and for the clinical picture to be typical, hence the interest, when faced with a picture suggesting an ASD:

- on the one hand, to verify that it is indeed an autistic syndrome and not another psychiatric syndrome and,

- on the other hand, to look for a possible psychiatric comorbidity. (Murad.A& All, 2014, pp 577-586)

The diagnosis and assessment of psychiatric disorders in autistic people are difficult because most of these people have communication difficulties and may also have mental retardation.

The diagnosis will largely depend on the identification of new symptoms and/or a worsening or qualitative alteration of existing symptoms. (Murad.A& All, 2014, pp 577-586)

Few questionnaires exist, those generally used to search for comorbidities are not adapted to autism due to the frequency of language difficulties and associated mental retardation. (Murad.A& All, 2014, pp 577-586)

Theoretically, there are several psychiatric disorders that can be: comorbid with autism in adults,

- Mental retardation;
- Schizophrenia;
- ADHD;
- Generalized anxiety;
- OCD;
- Social phobia;
- Mood disorders;
- Personality disorders;
- Language disorders;(Murad.A& All, 2014, pp 577-586).

Non-psychiatric comorbidities: Known genetic diseases such as:

- Tuberous sclerosis,
- Fragile X syndrome,

- Angelman syndrome; **UNDERSTANDING AND SOCIAL INCLUSION**

- Various chromosomal or genomic abnormalities;
- Epilepsy. (Barthélémy & Bonnet, 2012, p 50-57)

Practically, few comorbidity studies exist due to the lack of knowledge of this pathology in adults. A study conducted in 2004 (Stahlberg et al. Reported in (Barthélémy & Bonnet, 2012, p 45)

on autistic adults found:

- 38% have ADHD.
- 7% have bipolar disorder with psychotic elements.
- 7.8% have schizophrenia or another psychotic disorder.

III– Management:

Little intervention research in adults and the studies published so far are of insufficient quality, with results providing a low level of evidence which limits the reliability of recommendations for practice. (Baghdadli, 2017, P 39-42)

Young adults & Adolescents who are diagnosed with autism spectrum disorder (ASD) often suffer the severe effects of social isolation and unemployment. There is a great need for social skills groups, but there are relatively few exemplary programs developed specifically for this age group.

Overall, there are two types of interventions:

- a. Psycho-social.
- b. Bio-medical.

A developmental alliance (according to the expression of G. Magerotte) to support the person throughout their life (instead of the therapeutic alliance which aims at healing). It is a palliative and not curative intervention, it does secondary or tertiary prevention.

The involvement of the autistic adult in the development of their Personalized Intervention Project (according to the saying which says: "What you do for me if you do it without me, you do it against me"). (Murad.A& All, 2014, pp 577-586)

Psychosocial interventions: Some improve the core signs of ASD in adults without intellectual disability (ID) or mild ID: social scenarios, social skills training group, or anxiety management.

CBT is ineffective on the core signs of ASD but can improve associated anxiety disorders (Baghdadli, 2017, P 39-42).

Biomedical interventions: Not recommended (in the absence of proof of efficacy) as a treatment for the core signs of ASD.

Psychotropic drugs: Symptomatically useful in the treatment of associated disorders but the evidence on their efficacy and tolerance is still weak. Antipsychotics are not anti-autism:

Risperidone: reduction of aggressive behaviors with strong evidence of adverse effects (sedation and weight gain).

Fluvoxamine: reduction of repetitive behaviors.

Fluoxetine: reduction of repetitive behaviors (35% in the experimental group vs. 0% in the control) (Baghdadli, 2017, P 39-42)

Integration: It differs between autistic people with or without mental retardation.

In general, the latter are better integrated with some relational difficulties in the workplace and society.

For autistic adults with mental retardation, there are in developed countries a set of organizations and centers that are intended for this segment of the population to facilitate their social integration but which may not be specific to autism, intended rather for any type of mental disability,

This is an example of the establishments existing in France:

- Specialized reception center (MAS);
- Medicalized reception center (FAM);
- Work assistance establishment and service (ESAT);
- Social life assistance service (SAVS);
- Medical-social support service for disabled adults (SAMSAH)
- Day care center (CAJ);
- Sheltered workshops (AP). (Murad.A& All, 2014, pp 577-586)

In other countries, particularly in the USA, Great Britain, and Canada, the following are offered:

Help with career paths and employability (search for and maintaining employment): Rare dedicated systems in the USA (CSAAC, Community Services for Autistic Adults and Children), GB (Prospect) or Canada (équitravail).

Help with residential autonomy;

Help with emotional relationships. (Baghdadli, 2017, P 39-42).

In this field an article led by Dr. Ashleigh Hillier and All (2007) evaluated the effectiveness of the Aspirations program, which aimed to enhance social and vocational skills among adolescents age and young adults on the autism spectrum. Self-report measures, including peer relationships and empathy, were administered before and after the social skills assessment. Additionally, structured observations of changes in input rates (by group members) throughout the program activities were analyzed. Data included summaries provided by staff as well as observation sessions with group members and their parents regarding the success of the program. Such findings attest to the adequacy of the Aspirations program and provide insight into how a practical model might be implemented for this population.

Data consisted of summaries provided by staff members and observation sessions with group members and their parents about how well the program was doing. These findings speak to both the sufficiency of the Aspirations program and the potential applicability of how practical implementations might look for this population.

As measured by the Empathy Quotient, which assesses a person's awareness of others' thoughts and feelings, participants showed significantly greater improvement in empathy. (Hillier, Fish, Cloppert, & Beversdorf, 2007, pp 107-115)

IV- Situations encountered in daily practice

According to our information, no published study has been done in our country (Algeria) on adult autistic people.

The clinical observation of the evolution of the children and adolescents that we follow in consultation is hampered by several obstacles:

- Our professional instability due to several transfers of the workplace with an almost radical change in the clinical population.

- The significant number of abandonment of the follow-up of our consultation.

- The urgency of dealing with autism in children due to a significant lack of specialized professionals, particularly child psychiatrists.

Some adolescents who have reached the age of majority, and who have passed into the adulthood period according to this definition, have remained almost the same with:

- Persistence of the symptoms they previously presented with a progressive improvement in social interactions in autistic people without mental retardation.

- Persistence of dependence on the family, in particular the mother who manages the daily life of her autistic son or daughter whether with or without mental retardation, and, the father who has a role when there are major behavioral disorders, particularly aggressive ones.

We worked in general psychiatry for about ten years (2006-2015).

We had little knowledge about childhood autism and no knowledge about autism in adults.

In retrospect, with our current knowledge in this field, we remember a few cases that we had seen in general psychiatry, considered as schizophrenics and mental retardation, and which are in reality very probably cases of autism.

V- Conclusion

The conclusion raises a crucial point: investment in the management and understanding of autism in adults is lagging, even in developed countries. This means that autistic adults are often overlooked in terms of support services, access to employment and education, and general understanding of their specific needs.

For our country, this represents an important learning opportunity. Rather than repeating the same mistakes and perpetuating this gap, it is essential to learn from the experiences of other nations. By examining what works elsewhere, we can identify effective strategies and policies to improve the quality of life of autistic adults in our society.

This involves a commitment to listening to and involving autistic people themselves in decision-making, as well as investing in awareness-raising and training programs for health, education, and employment professionals. By taking a proactive and inclusive approach, we can avoid creating an even wider gap between the needs of autistic adults and the resources available to support them. Ultimately, this will benefit not only autistic adults but society as a whole by promoting greater diversity, inclusion, and, equity.

Awareness-raising work, and even training, is needed among adult psychiatrists to improve the diagnosis and care of autistic adults.

Autism strategies and plans must contain a chapter dedicated to this age group.

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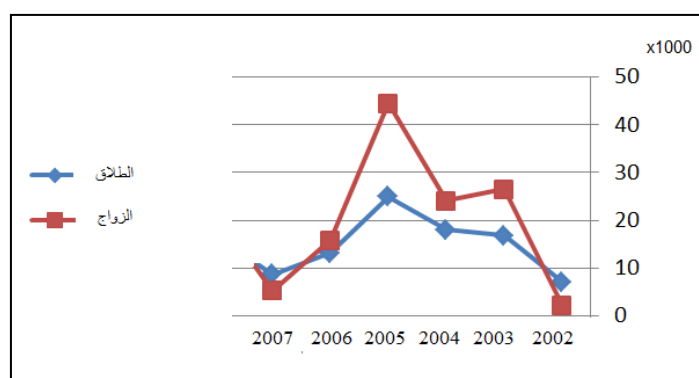
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Table (1) : The number of publications on Autism Spectrum Disorder (ASD) by Age group.

Age Group	Number of Pub
Children	12,000
Adolescents	5,500
Adults	4,000
Older People	100
Total age spectrum	18,000

The source :

Figure (1): The Figure Title



The source :