

## Autism Spectrum Disorder in Algeria. Schooling of autistic children. Current situation

اضطراب التوحد في الجزائر. وضع تـمدرس الأطفال المصابين بالتوحد

Sail Hadda Ouahida <sup>1,\*</sup>, Hamadou Hala <sup>2</sup>

<sup>1</sup> Algiers2 University(Algeria), o.sail@univ-alger2.dz

<sup>2</sup> Algiers2 University(Algeria), halahamadou2000@gmail.com

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### Abstract :

Autism was not known as a neurodevelopmental disorder with special needs as it is now, hence some delay is observed in the implementation of the care of autistic children as a fringe that has need continuous support and accompaniment in all areas of life, especially with regard to education in early life. The objective of this paper is to shed light on the current situation

of autism spectrum disorder in Algeria, including available statistics on the prevalence of the disorder and its early diagnosis. Our interest is mainly focused on the schooling of autistic children in mainstream schools, given the importance of education and learning in early life.

**Keywords:** Autism- child- adolescents- schooling

### 1. Introduction

Autism Spectrum Disorder [ASD] is considered a neurodevelopmental disorder that manifests in early childhood and develops throughout life. This disorder occurs during early childhood and affects the ability to communicate and reciprocal social interactions. ASD (American Psychiatric Association, 2013) characterized by deficits in social communication and the presence of restricted interests and repetitive behavior (Cited by Hodges, Fealko & Soares, 2020).

Two types of autistic manifestations have been identified, known as the autistic dyad (Baker & Jeste, 2015 ):

Difficulties in communication and social interactions, where verbal language is sometimes delayed or absent, insufficient nonverbal communication, repetition of certain words or phrases, poor understanding and difficulty expressing one's own emotions and understanding the emotions of others, discomfort in social interactions...

Repetitive behaviors and restricted interests, such as repetitive or compulsive movements, intolerance to changes, unexpected or obsessive interests or activities...

These manifestations are often accompanied by an excess or a deficiency of a sensory response, people with autism can react intensely to sensory stimuli (noise, light, smell, touch, etc.) or, conversely, show little of sensitivity.

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\*Corresponding author

Additionally, autism can be accompanied by other manifestations, thus constituting comorbidity: sleep disorders, mental disorders (anxiety, depression, etc.), other neurodevelopmental disorders of learning and attention (hyperactivity...), epilepsy and certain genetic disorders (Down syndrome, Rett syndrome, fragile X syndrome, etc).

So, if this observation concerns developed countries, what about developing countries, in Algeria particularly? What is the current situation regarding the prevalence and care of people with autism disorder? What about the schooling of autistic children?

But before presenting the current situation, it is important to provide a historical overview and classification of autism spectrum disorder.

## 2. Historical overview

It is important to start at the beginning. Autism was not known as a neurodevelopmental disorder with special needs as it is today. Therefore, there was a relatively delayed implementation of support for autistic children as a group in need of continuous support and assistance in all areas of life, especially in terms of education and early-life learning.

Autism was long considered a mental illness (Cited by Lenoir et al., 2007). In 1895, Kraepelin described "early dementia" which corresponds to the future concept of schizophrenia, named as such by Bleuler in 1911. Sancte de Sanctis, in 1906, described a similar condition in children aged 4 to 10 years, that he called "dementia precocissima" or "early dementia". Also, Theodore Heller, observed in 1908 a phenomenon of regression of achievements in children aged 2 to 4 years to whom he also applied the concept of dementia. Finally, the notion applied to the childhood schizophrenia will be developed by Potter in 1933, Lutz in 1937, and Despert in 1938, at the dawn of Kanner's publication. During the first half of the twentieth century, psychoanalysts widely used the term "infantile psychosis" which was the dominant paradigm. The theories of Melanie Klein gave rise to the English school of child psychoanalysis, whose followers continue to enrich their work despite the new concepts published by Kanner. In 1943, the American child psychiatrist Kanner published 11 cases of children exhibiting a common and specific character: the social contact disorder of social contact characterized by the main symptoms: "aloneness" or isolation, withdrawal, and "sameness" or the desire for immutability and intolerance to change. Bleuler had already used the term "autism" to designate one of the symptoms of schizophrenia. Kanner uses this expression to designate a pathological entity called "early infantile autism". The following year, the Viennese psychiatrist Hans Asperger published six cases of "autistic psychopathy" (Lenoir, Malvy & Bodier-Rethore, 2007, p.4).

Following Kanner's work, nosographies have appeared to describe autism disorder based on semiology and behavioral observation to ensure a more objective approach to the disorder.

### 3. Classification of Autism Spectrum Disorder

A classification of autism (Cited by Borelle, 2013) was introduced earlier in 1980 in the third edition of the American Psychiatric Association's DSM (DSM-III, APA, 1980). Then in the International Classification of Diseases (ICD-10) by the World Health Organization (OMS, 1992). Additionally, the French Classification of Mental Disorders in Children and Adolescents [CFTMEA] considered it as an infantile psychosis in 1993, and it was only in the revised classification of the CFTMEA in 2000, that the description of autism became closer to international classifications, considering it a developmental disorder.

According to researchers, although it was long regarded as a mental illness, Pervasive Development Disorders [PDD] is now described as a neurodevelopmental disorder associated with a complex genetic predisposition (Bacchelli et al., 2003; Rogé et al., 2008). A predisposition that can be impacted by many neurological and environmental factors (Lin, 2011) (cited by Pierre Leblanc, 2013, p.13).

Therefore, autism spectrum disorder is not a mental illness, it is a disability that requires specialized care from the early years of life and continuous support.

On the basis of this evolution, considering the Convention on the Rights of the Child and the Convention on the Rights of Persons with Disabilities, according to which children with disabilities should lead a full and decent life in conditions which guarantee their dignity, promote their autonomy and facilitate their active participation in the community life, as well as the full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, the General Assembly (AG) of the United Nations (Nations Unies, 2008) proclaimed April 2 World Autism Awareness Day (A/RES/62/139) to draw attention to the need to improve the quality of life of people with autism, so that they can lead rich and fulfilling lives as an integral part of society. This convention is a strong tool to establish a generous and inclusive society, and to ensure that all children and adults with autism have a normal and fulfilling life. Noting that the GA is aware that autism is a lifelong developmental disorder that manifests during the first three years of life and results from neurological dysfunction that compromises brain function, affecting primarily children without distinction gender, race or socioeconomic status, in many countries, and which is characterized by impaired socialization and verbal and non-verbal communication, restricted and repetitive behaviors, interests and activities.

Autism spectrum disorder is considered by the American Psychiatric Association in the DSM-5 (2013) (Cited by HAS, 2018) as a neurodevelopmental disorder, whose diagnostic criteria are noted in the first category: Deficits persistent problems in communication and social interactions observed in various contexts (deficits in social or emotional reciprocity, deficits in non-verbal communication behaviors used during social

interactions, deficits in the development, maintenance and understanding of relationships). Also, in the second category we find the restricted and repetitive nature of behaviours, interests or activities (stereotyped or repetitive nature of movements, in the use of objects or language, intolerance to change, inflexible adherence to routines or ritualized verbal or nonverbal behavioral patterns, extremely restricted and fixed interests, abnormal either in intensity or purpose, hyper- or hypo-reactivity to sensory stimuli or unusual interest in sensory aspects of the environment) (Haute Autorité de Santé, 2018, p. 141).

In addition, recent studies estimate the average prevalence worldwide according to the World Health Organization (WHO, 2013) that approximately one child in 160 has an autism spectrum disorder and associated disability. These estimates represent the average number of cases, and prevalence rates vary widely between studies. But some recent studies report much higher prevalence rates. The level of mental performance of people with autism spectrum disorders is highly variable and ranges from severe to major deficits in the patient's non-verbal cognitive skills. It is estimated that around 50% of people with these disorders also have intellectual disabilities (Organisation Mondiale de la Santé, 2013).

The World Health Organization (2023) also states that Autism Spectrum Disorders are a diverse group of disorders, the signs of which can be detected in early childhood but are usually diagnosed at a later stage. The abilities and needs of people with autism vary and may change over time, while some may be able to lead independent lives, others have severe disabilities and require lifelong care and support. Evidence-based psychosocial interventions can improve communication skills and social behavior with a positive impact on the well-being and quality of life of people with autism and their caregivers. These people are also often victims of stigma, discrimination and human rights violations, and it is essential that targeted care is accompanied by social and community measures to facilitate include and support these people (Organisation Mondiale de la Santé, 2023).

Despite the efforts made for years in developed countries, the number of people with autistic disorder is constantly growing. These countries have adopted early diagnosis of the autism spectrum and organized methods of care for children affected from the first years of life as soon as the first signs of the disease appear. These procedures are governed by legislation. What about low and middle income countries? Our reading of what is available online indicates that all autism statistics are unknown in these countries. In particular on the potential care of people with the autism spectrum in these countries, especially in the case of autistic children, and what about Algeria, what is the extent of autism spectrum disorders. How are autistic children being cared for?

#### **4. Autism situation in Algeria**

In Algeria, little is known about autism, and access to care institutions for autistic children remains difficult, due to the lack of institutions specialized in the reception of

autistic people. Also, the lack of professionals trained in autism, and the lack of carers... who can accompany children with autism in their entourage and in schools.

Thanks to associations and some individual's goodwill, awareness of the importance of specialized centers and access to ordinary schools has seen a certain clarity. However, some schools have accepted the opening of specialized classes to accommodate children with autism (Guelai, 2015, p. 50).

For his part, Ouled Taleb (2016) states that one in 300 children has an autism spectrum disorder which is a public health problem. The authorities are more than ever challenged to put in place a special care and follow-up plan for autistic people. He affirms that for ten years the Eric Shopler program created during the 1970s in North Carolina has been applied. Since 1997 to date, 6,000 cases of children and adolescents with autism have been recorded. Early diagnosis is crucial for prevention. Because if the autistic child is not taken care of between 2 and 5 years old, the mental retardation is irreversible if screening is not done in time. Children over 6 years old cannot be taken care of. In 2013, 14,000 consultations were recorded against 16,000 in 2014. In total, 5,000 new cases are recorded each year. With a deficit of 10,000 places, it is a tragedy. Algeria is 50 years behind. Autistic children who can more or less be associated with other children at school suffer from stigmatization, which also delays the therapeutic process...

The National Center for Studies, Information, and Documentation on Family, Women, and Childhood (2019), declares 2,963 autistic children during the year 2018-2019 (719 girls and 2,244 boys ), or (24.27% - 75.73%) in psychopedagogical centers for mentally handicapped children. Of which, 1,861 are aged 6 to 10 (62.81%), 519 children aged 11 to 14 (17.52%), and 465 children are aged 03 to 05 (15.7% ) lastly 118 people aged 15 to 18 (3.98%). The distribution of autistic children during the first six months of 2018 in centers specializing in mental illness shows variable rates, 30.7% in the center of Blida, 25% in the center of Oran, 13.2 % in the center of Annaba, 12.4% in the center of Constantine, and 11.7% in the center of Drid Hocine and 7% in the center of Chéraga. Also, 274 adherent members of the National Association of Autism Disorders were registered in Algeria during the year 2018, of which 78% are parents of autistic children, 14% specialists, 5% volunteers, and 3% were specialists and parents of autistic children at the same time ( وزارة التضامن الوطني والاسرة وقضايا المرأة. المركز الوطني للدراسات والاعلام والثوثيق حول ( الاسرة والمرأة والطفولة.2019).

The Turkish Cooperation and Coordination Agency (TIKA) (2020) reported that according to the statistics of the Algerian Ministry of Solidarity of 2019, an estimate of 3,000 autistic children, of whom 465 in the early intervention phase (aged 3-5 years), these children are cared for in psychological centers for mentally handicapped children throughout the national territory, but these centers are not specialized in the education of this group of children. Algeria suffers from a significant deficit in centers specializing in

the care of autistic children, there are 3 experimental centers, which are located in the wilayas of Algiers, Bouira and Constantine (2020, وزارة الثقافة والسياحة التركية, [Turkish Ministry of Culture and Tourism]).

As part of the Algerian-French Profas C+ Program, in particular the support project for the screening, diagnosis and management of autism in Algeria (Autisme PROFAS C+) (Expertise France, 2021), the consequences of the disorder autism are considered quite burdensome both for the people affected, their families and the community. In many cases and in the absence of early treatment, the condition can lead to varying degrees of mental and social disabilities. Autism Spectrum Disorders (ASD) are one of the leading causes of mental disability in children aged 5 to 14. In Algeria, it constitutes a major public health problem due to its extent, its consequences and the demographic characteristics of the current population and using the demographic data of the National Statistics Office (ONS) for 2015, there would be nearly 400,000 people with autism. Today, the possibilities for diagnosis and management of individuals affected by autism remain insufficient. The evolution of children is still most often towards a more or less marked mental and/or social disability. In rare cases, they are able to attend school but face numerous difficulties. The issue has therefore become an important concern for the authorities in charge of health and education. This includes improving the diagnosis and care of people affected by autism, in line with international recommendations in this area. Interesting experiences in public health, in national solidarity and local associations (parents associations of children with autism, psychoeducational care centres) could constitute, if they are reinforced, the backbone of the care system.

In this context, our interest is focused on the situation of education and schooling of children with autism spectrum disorders, since it is a basic need at the beginning of children's lives.

### **5. Education of autistic children in Algeria**

According to available sources, Algerian legislation covers everything related to the rights of children and people with disabilities. Through legal texts, Algeria the application of the right of children with disabilities to education and learning by insisting on equal opportunities in its report to the United Nations. On the rights of persons with disabilities, published on the United Nations website in 2015 (Nations Unies, 2015). However, what was the situation before that year, and how has it evolved after Algeria's ratification of the international convention on the rights of persons with disabilities, especially children?

The Algerian state has put in place a set of systems to ensure the education of disabled children according to the nature and degree of their disability. This is how these children are taken care of, either by specialized establishments, under the supervision of the Ministry of National Solidarity, Family Women's Affairs, or by schools of the Ministry of National Education where they benefit from partial or total integration. In this regard, integrated classes are open in certain schools throughout the national territory in order to

take charge only of children suffering from sensory disabilities (reduced hearing and visual capacities), and this, in application of the interministerial decree of the December 10, 1998, as part of the integrated approach (Ministère de l'éducation nationale, 2021).

In 2002, Law No. 02-09 of May 8, 2002, was published relating the protection and promotion of persons with disabilities. of which art.3, relating to the protection and promotion of persons with disabilities, states as one of its objectives is the provision of compulsory education and vocational training for children and adolescents with disabilities (Journal officiel N° 34 du 14 mai 2002, p. 5).

In 2008, Law No. 08-04 of January 23, 2008 on the orientation law on national education was published, art.10 mentions that the state guarantees the right to education to all Algerian citizens without discrimination based on sex, social origin or geographical origin. Art.11 mentions that the right to education is concretized by the generalization of basic education and by the guarantee of equal opportunities in terms of schooling conditions and continuation of studies after basic education. Art.12 mentions that education is compulsory for all girls and boys aged 6 to 16 years old. However, the duration of compulsory schooling can be extended by two (2) years, as needed, in favor of disabled students (Journal officiel N° 04 du 27 Janvier 2008, p.9).

A presidential decree n° 09-188 of May 12, 2009 was also published concerning the ratification of the convention on the rights of persons with disabilities, adopted by the United Nations General Assembly on December 13, 2006 (Journal Officiel N° 33 du 31 Mai, 2009). Art.3 emphasizes respect for difference and acceptance of people with disabilities as part of human diversity and humanity, and considers equal opportunity and respect for the development of life skills of the disabled children, and respect for their right to preserve their identity (p. 5). Art.7 envisages necessary measures to guarantee children with disabilities the full enjoyment of all human rights and fundamental freedoms, on an equal basis with other children (p. 6). Art. 24 on education, contemplates the right of persons with disabilities to education. With a view to ensuring the exercise of this right without discrimination and on the basis of equal opportunity, and provides lifelong educational opportunities. Persons with disabilities are not excluded, on the basis of their disability, from the general education system, from free and compulsory primary education or from secondary education on an equal basis with others. Persons with disabilities benefit, within the general education system, from the support necessary to facilitate their effective education. Effective individualized support measures are taken in environments that optimize academic progress and socialization, in accordance with the objective of full integration. States Parties shall provide persons with disabilities with the opportunity to acquire the necessary practical and social skills to facilitate their full and equal participation in the education system and in the life of the community (p. 10).

However, this decree is focused on sensory disability in particular, and does not extend to autism disorder, knowing that autism spectrum disorder is particular, it requires and deserves a particular understanding especially in matters of schooling. The communication deficit in these children requires a particular interest which must be taken in social skills, as well as a training of the interveners in the schools in order to allow these children an adaptation to the school environment and the acquisition of the skills in real time. So, until now, the term autism disorder is not mentioned in legal texts.

The interministerial order of December 10, 1998, opening special classes for children with sensory disabilities (reduced hearing and visual abilities), was repealed by an interministerial decree of March 13, 2014, specifying the procedures for opening classes for disabled children, within public educational establishments in the national education sector. These classes are opened by joint decision established between the director of social action and solidarity of the state and the director of education of the state. These special classes accommodate children with hearing and visual disabilities, as well as children with mild mental impairment (Journal officiel n° 44 du 27 Juillet 2014, p. 26).

In the context of autism, all of these texts explicitly deal with specific sensory disabilities, and the term "autism spectrum disorder" only appeared in 2019, despite the allocation of special classes for people with special needs, this may explain the lack of statistics on the prevalence of this disorder despite the suffering of parents, who found themselves faced with obstacles that prevented their children from benefiting from early diagnosis and appropriate education for many years.

The president of the National Association Autism Algeria, Ouali Laila, stated in newspaper El Watan (El Watan, 2017) that in the absence of adequate support from the public authorities, the parents of autistic children are trying, each according to their means, to save their children by offering them an adequate framework, at present there is total confusion: in addition to "the absence of a clear strategy and the non-application of the guidelines of guardianship", Algeria is only copying "the French experience which itself lags behind in this matter".

For the first time, the term "autism spectrum disorder" appears in a regulatory text at the insistence of autism disorder associations founded by parents of autistic children, and according to all data in their sequence chronologically, an interministerial circular n°1 was published on September 03, 2019, relating to a reminder of the measures and provisions relating to the education and training of children with special needs, this text recalls that the education and training of these children constitute a constant concern of the state in order to enable them to exercise their constitutional right to education, teaching and training, just like other Algerian children, a right enshrined in law 09-02 above mentioned. The protection and promotion of persons with disabilities aims to ensure compulsory schooling and vocational training for children and adolescents with disabilities. This circular specifies the provisions relating to the opening of a special class,



and the disabilities concerned are: sensory disability (hearing, visual), mild intellectual disability, including trisomy 21, and mild autism disorder (2019, *التشريع المدرسي الجزائري*).

When the condition of a child with a disability or disorder requires the accompaniment of a School Life Assistants (SLA) on the confirmed opinion of the attending physician, the guardian of the child concerned must establish a request for the provision of assistant with the direction of social action and solidarity in order to ensure the continuity of good schooling.

The School Life Assistants SLA, is responsible for:

- Accompany the student to access the school and the classroom and to move between its different spaces,
- Help the student to organize his work,
- Help the student with educational tasks (writing, notation, drawing, simplifying and explaining the questions asked, clarifying what the teacher is asking, participating in group work...),
- Accompany the student in physical education and sports activities,
- Accompany the student during recess and intervene in case of emergency for the student concerned,
- Accompany the student in cultural, sports and entertainment activities and in exploratory outings.

In general, the SLA plays a role in the student's learning path, their interaction with other students and their integration into the school environment. In addition to the role they play in the school, he ensures the link between the student and his family with regard to the educational, relational and learning aspects.

The success of the SLA in its mission depends on the support they receive from the educational team in the school establishment. Their presence is crucial in overcoming obstacles that hinder the education of students with disabilities or disorders and ensuring equal opportunities in education for all students.

The integration of SLA is a recent challenge in the Algerian education system. While awaiting the emergence of a legal text on the subject, until then, the school director and teachers must facilitate the task of the SLA and assist it in its accomplishment by ensuring the appropriate conditions for the normal schooling of the child concerned.

However, this interministerial circular does not refer to the specificity of autism disorder, requiring the child to be accompanied by an SLA for national exams, which is not provided for this type of disorder. Despite this, the provisions provided for in this text can be considered as a first and good initiative of the ministries concerned which could lead to other regulatory legal texts according to the needs and an evolution in the field of education and training for people with autistic spectrum disorders.

On September 20, 2021 (Algérie Presse Service, 2021), a press release from the Prime Minister's office indicated that the Minister of National Solidarity, Family and the Status of Women announced during the government meeting, the opening of 238 special classes at the three levels of education (from basic education while providing them with support from school medicine) for the benefit of children with autism spectrum disorders in anticipation of the start of the 2021 school year- 2022.

On this occasion, the national solidarity, education and health sectors initiated a series of measures for the benefit of these children, aimed at ensuring their schooling in the best conditions and allowing their full integration. Facilitation measures granted for the benefit of students with autism spectrum disorders, by allowing them to be accompanied and assisted by SLA, on the occasion of national examinations.

It is a great victory for the parents of these children who for years have been demanding such a decision, as it means that their children will now have the right to a normal schooling.

The number of autistic children in Algeria is constantly increasing, while the means of screening and especially of care remain inadequate. Hoping for the guarantee of education and learning adapted to autistic children throughout all the states of the country.

## 6. Conclusion

Autism Spectrum Disorder is a neurodevelopmental disorder characterized by deficits in communication and social interaction, as well as restricted and repetitive behaviors, interests or activities.

Since the 2000s, Algeria has shown particular interest to individuals with specific needs, and ratified the United Nations International Convention in favor of these individuals in 2009.

However, when it comes to autism, early detection, education and schooling for this segment of children remains very modest.

This disorder is not necessarily linked to mental retardation, so giving these children the chance to follow a regular education can only increase their chance to flourish in their lives, in their education and bring something more to society.

Since the first description of this disorder in 1943 to date, it is known that many of them are endowed with extraordinary intelligence. They work miracles when they are well taken care of.

Nowadays, it is known that children with the autism spectrum have hypersensoriality and hypersensitivity and pay attention to micro-detail, which allows them to make great achievements, each in their field. To say that this sensitive fringe of

society can be an important force for their country, if you give them the chance to realize themselves.

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