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AUTISM IN ALGERIA: FAMILY EXPERIENCES, QUALITY OF LIFE, AND FUTURE DIRECTIONS

Nadia Cheradi [1] **Antissar Sahraoui** [2]
[1] **University of Blida 2 (Algeria)**
n.cheradi@univ-blida2.dz

[2] **University of Bejaia (Algeria)**
Mental Health and Neuroscience Laboratory
antissar.sahraoui@univ-bejaia.dz

Abstract : The incidence and prevalence of pervasive developmental disorders, particularly autism—with its etiology still far from fully understood, its polymorphic, complicated, and complex semiology, and its harmful consequences that affect not only the child but also the family dynamics as a whole and its functioning, which had been established until his arrival - appear to be among the major priorities of global health organizations, especially those concerned with the physical and mental health of the child and their family. Currently, the care of autistic children in Algeria presents challenges linked to challenges related to parental experiences**,** the lack of resources, trained health professionals and suitable structures, but great progress and initiatives are underway to improve the situation. However, certain important and decisive aspects seem to be overlooked, minimized, or marginalized, such as the suffering of parents and families of children with autism, which remains underestimated and poorly taken into consideration, particularly within Algerian society. However, following the family's adaptations, it moves towards one of the two opposing poles: ″resilience″ and ″invasion″ by pathology. Our objective is to attempt to give meaning to and shed light on this particular suffering by seeking to answer the following questions: Who are these families, and what are their particularities? How do they organize themselves around the symptom of ″autism″? How do they present in consultation?, What is the quality of life of the siblings? And finally, what is the reality and what are the perspectives of autism in Algeria? This qualitative study utilized data from semi-structured clinical interviews with parents of children with autism and was analyzed through content analysis informed by thematic analysis (Bardin, 1977). This approach enabled us to explore and interpret findings pertinent to the Algerian context.

Keywords: Autism, developmental disorders, parental reactions, siblings, quality of life, Algeria, Bardin thematic analysis

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[1] **Corresponding author** :Nadia Cheradi **Authors' ORCID ID:** https://orcid.org/0009-0000-3410-6258

1. Introduction

The birth of a child with a disability or developmental delay often shocks parents, profoundly disrupting their lives. Parents must learn to live with and adapt to a « different » and » challenging » child, constantly worrying about their development, well-being, and future. They face a shock that forces them to mourn and adjust to a new reality in contrast with the child they had imagined during pregnancy : raising an autistic child who requires specialized, complex care. Parents often experience prolonged or intermittent stress, which can negatively affect the dynamics of the couple and the entire family.

The difficulty of the situation is not only due to the shock of the diagnosis and the adjustment that follows, but also to the consequences of the disorder: parenting tasks that prove to be more onerous than those faced by parents who are not spared this kind of problem. Similar to medical appointments, administrative procedures, and coordination with schools and specialized institutions, this organizational burden is accompanied by a significant emotional load (Boursange & Gargiulo, 2022, p. 15).

Furthermore, the parents of children with autism often face a range of challenging behaviors, including agitation, screaming, stereotypes, self-mutilation, difficulties with feeding and sphincter training, insomnia, and more. When autistic symptoms are severe, these can significantly affect the child's motor development and social integration, leading to challenges in mobility outside the home.

Accordingly, research conducted by Fisman and Wolf (1991) and Dyson (1997), has demonstrated that parenting a child with a disability, particularly one with a pervasive developmental disorder. Is often associated with elevated stress levels, diminished mental health (Weiss, 1991; Fisman and Wolf, 1991), and reduced physical functioning, including fatigue or even exhaustion, in both mothers and fathers (Hedov, Annaren & Wikblad, 2000; Emerson, 2003). (Cappe,2009, p.209).

In recent times, Bobet and Boucher (2005) demonstrated that the developmental and social challenges faced by children with autism, along with the daily stress associated with their condition, significantly impact the parents' quality of life. This impact is particularly evident in the organization of daily routines and leisure activities,…, as raising a child with autism often limits personal time, necessitating a rigid and exhausting daily schedule.

Moreover, the suffering of parents is closely linked to the negative social image and critical perceptions of their child by those around them, stemming from the challenges of managing their child's behavior. This can lead to narcissistic injury, frustration, anxiety, powerlessness, injustice, and guilt—emotions that may ultimately result in isolation and the avoidance of social contact, including declining invitations. Parents find themselves not only coping with the distress of having a child with autism, but also dealing with the stigma of being perceived as inadequate, inappropriate, or 'bad' parents. The degree of isolation often correlates with the severity of the disorder, particularly behaviors such as agitation, bizarre actions, and stereotypes, which prompt parents to avoid interactions with others to prevent judgment and stigma.

In reality, this is a complex situation of extreme suffering for parents faced with a disorder that is often unknown or unrecognized, putting them in a position of warmongering or isolation experienced with distress and shame. The impact on the family can range from the appearance of disorders such as stress or depression in one or both parents, to the total reorganization of family functioning, starting with the management of daily life, the couple's relationship, and the family dynamic involving siblings, grandparents, and the extended family.

From this standpoint, Beson (2006) notes that the mental health of parents depends on both the severity of symptoms and the extent to which autism spectrum disorder affects their daily functioning. The more severe the autistic symptoms, the greater the impact on the parents' daily lives and mental health. On the other hand, the author shows that ‘informal’ social support (family, friends, etc.) reduces the negative effects of autistic disorder on parents' daily lives and mental health; this effect of “informal” social support is all the more important when autistic symptoms are mild (Cappe,2009,p. 210).

Therefore, the role of the environment is crucial in this context, in the literature review, researchers highlighted the significant relationship between social support and a reduction in stress for parents of autistic children. Conversely, low social support is a predictor of depression and anxiety, particularly in mothers, with informal support (family, friends) having a more substantial impact on stress reduction than formal support (professionals).

With respect to the recognition of autism in everyday Algerian discourse, despite the fact that the concept of autism has existed globally since it was first identified by L. Kanner (1943), it remains relatively unknown and vague . Only in recent years has autism started to be discussed more openly in the media, as its growing prevalence has become a significant public health and social issue. Individuals with autism often live in the shadows of anonymity, a curious paradox; even on national and international days dedicated to people with disabilities, they are frequently overlooked by society. It is only due to the advocacy of specialists and associations of parents of autistic children that the topic has begun to gain attention.

Despite the presence of this multifaceted syndrome, which affects an increasing number of individuals, no official prevalence statistics are available for autism in Algeria. Some specialists estimate that out of a million people—children, adolescents, and adults—with a mental disability, 49,000 are autistic. Others suggest that between 60,000 and 70,000 individuals are affected by autism, which disproportionately affects boys at a ratio of four to one compared to girls. Professor Ould Taleb, a child psychiatrist at Drid Hocine Hospital in Algiers, estimates the number of autistic teenagers in Algeria to be around 65,000, a figure that continues to rise given the number of children seeking consultations for screening or suspected diagnoses.

This situation led us to ask the following questions:

How can parents respond? How do they manage to adapt to this disorder? What are their needs? What is the impact of this disorder on siblings?

This contribution is the result of our practice during consultations at the Autism Association

This study, conducted in the Province of Constantine, Algeria, examines the characteristics of families with children with autism, their experiences, and the impact of the disorder on family dynamics and siblings, drawing on relevant theoretical frameworks and clinical data, with the aim of identifying and highlighting the profound suffering that often goes unnoticed or inadequately recognized by practitioners. Professionals, and researchers often fail to notice or misperceive. Recognizing this is crucial for involving parents in any form of care, especially when dealing with this disorder. Without the involvement, information, and motivation of parents, any treatment attempt is bound to fail.

This paper draws on clinical consultations with parents of children with autism, through which we sought to break down and understand their emotions, as their reactions were highly nuanced. Subsequently, we attempted to analyze the behaviors and responses of the families, particularly within the sibling group.

2. Method

At our center, we care for over 100 children with autism, 60 of whom are aged between 4 and 16 years. These children receive treatment from our multidisciplinary team, which includes psychiatrists, psychologists, speech-language pathologists, and nurses, at a newly opened day hospital designed specifically for individuals with autism, in the Province of Constantine, Algeria.

The families of these children have varying levels of education, with fathers' ages ranging from 34 to 62 years and mothers' ages from 30 to 54 years. Most of the children diagnosed with Kanner's autism display challenging behaviors and lack language skills. Other children exhibit characteristics of Asperger syndrome or hyperactivity with concentration difficulties.

Table 1.

Summary of the Study Population

Characteristics	Details
Parents’ age	Fathers: 34–62 years Mothers: 30–54 years
Level of education	Middle school High school diploma University degree
Children’s ages	4–16 years
Child’s diagnosis	Kanner syndrome Asperger Syndrome Hyperactivity

The study population comprised 50 families with a child diagnosed with autism, with the primary inclusion criterion being the child’s autism diagnosis. Participants were recruited on a voluntary basis and could withdraw from the study at any time. Many parents attended consultations at the association seeking guidance on providing appropriate care, requesting hospitalization, or pursuing treatment for their child. Others participated primarily due to concerns about their child’s schooling. notably, only five of the children in our care are currently attending school, one of whom receives additional support from a school life assistant. Meanwhile, 25 children receive medical and psychological care, while the remainder consult psychiatrists only, due to limited resources or travel difficulties.

Our study is grounded in qualitative research, which does not aim to provide exhaustive results but remains essential for understanding complex phenomena. We primarily relied on data collected from semi-structured clinical interviews with parents of children with autism.

The study aimed to explore the psychological processes experienced by parents, their reactions to the announcement of the diagnosis, adaptation strategies, quality of life, marital relationship, interactions with siblings, and the role of the broader environment (extended family, institutions, etc.).

Interviews were conducted in dialectal Arabic, with follow-up questions posed when necessary to clarify responses. All interviews were recorded, anonymized, and analyzed using content analysis inspired by Bardin's thematic analysis (Bardin, 1977). This approach allowed us to examine and interpret significant information, recurring patterns, and emergent themes, with results presented according to these identified themes.

Consequently, we sought to break down the nuanced feelings experienced by parents and to analyze family behaviors and reactions, particularly within the sibling group.

3. Results and Discussion

3.1. Parents' Reactions to Autistic Disorder

According to Golay and Assal (1993), the process of accepting an illness or disorder can be very lengthy and involves four main stages, which are not linear or chronological: the initial shock, the denial stage, the stage of despair or depression, and the acceptance stage. We believe that this model can be applied to the parents of a child with an autistic disorder, in the same way it has been applied to other chronic conditions. (Cappe, 2009, p.227).

- The initial shock: Parents are generally alerted by the absence or delay in language, communication problems, avoidance of eye contact, lack of social interaction, delayed psycho-motor development, hypersensitivity to certain noises, repetitive play, and stereotyped behavior. Despite the presence of these signs, the announcement of the diagnosis by the doctor represents a traumatic event for the parents. Detecting the disorder and receiving the diagnosis is a difficult moment, but sometimes parents feel relieved when they finally understand what their child is suffering from. However, even if some parents request a quick response to the diagnosis, it is essential to respect the pace and approach of each individual.

- The stage of denial of reality is particularly invoked by the psychoanalyst Sigmund Freud. It is a defense mechanism in which the subject refuses to acknowledge the reality of a traumatic perception (Laplanche & Pontalis , 1973, p.115).

It is used to deny the diagnosis in order to reduce anxiety, As an illustration, we noted that in some instances, after the first consultation, parents may seek another diagnosis from a different doctor, which can delay professional intervention.

- The stage of despair or depression is closely linked to the isolation of the parents, the feeling of guilt, which is often perceived as a divine power or a punishment from God, and the sense of failure in the face of a child who is different. This feeling is reinforced by the heavy daily tasks, which are both morally and physically exhausting.

- In the end, the parents accept the disorder and come to terms with living with it. To reach this point and manage their child's disorder, they must mourn the loss of an idealized, imaginary child, one who embodies their parents' desires. **(**Boussafsaf , Metz ,2024, p. 106).

In this process, it is crucial that caregivers offer support to help the parents reflect on their child, their past, and their future. Additionally, it is important not to overlook the personal beliefs and representations of the disorder, as these shape the parents' reactions and can significantly influence the success or failure of treatment. We would like to emphasize one important point: the research of mourning or acceptance process is never fully complete in the population we encounter in our practice.

We have also observed that in our society, parents tend to rely on strategies based on their religious beliefs. The more they depend on their faith, the better they are able to understand and accept the situation, freeing themselves from guilt: disability becomes perceived as a matter of destiny. As a result, many parents find support and assistance through their religious beliefs.

Concerning the psychological experiences of parents, studies have shown that increased anxiety and depression in mothers contribute to heightened stress in fathers, as the presence of one anxious or depressed parent can undermine the support the other might rely on, leading to additional stress. In our study, we identified 10 women out of 50 who had experienced severe depression requiring treatment. Mrs. G, the mother of a 3-year-old autistic child, who is depressed and undergoing treatment, serves as a notable example, stating, "My son is autistic; he will never be like the others, no mater what I do..."

3.2. Quality of Life

In terms of research on families of children with autism, within the fields of psychology and psychiatry, is relatively recent, and there are limited references available. However, existing studies tend to focus on two main themes: the impact of autism or Asperger's syndrome on the family's daily life, and the coping mechanisms and strategies developed by family members. It has been observed that most studies focus on mothers and their well-being, as they are more likely to participate in research related to this condition

In our practice, we have found that many women interrupt their professional careers or take a leave of absence for several years. Following the diagnosis was announced, the mother often reshapes her entire life to focus to take care of and on raising her child, with all other aspects taking a secondary role, and her personal and professional life becoming increasingly dominated by concerns about the child's well-being and future. However, Mothers typically focus on their child's cognitive development, lack of independence, dependence, behavioral problems (self-stimulation, angry outbursts, aggressive behavior), and difficulties in integrating into society.

This is confirmed by the results of a study by Blanchon and Allouard (1998),indicate that more than half of mothers, because of the day-to-day difficulties associated with their child's autistic disorder, sacrifice their working life (50%), devote less time to their leisure activities (60%) and their social life (55%), and have significant physical (50%, of which 15% are serious) and mental (87%, of which 34% are serious) health problems (Cappe,2009,p.213).

In contrast, fathers' lives tend to be less affected. Their professional situations generally remain unchanged, as they continue to work to meet the family's needs for the child's education and care.

Similarly, a notable distinction is that mothers are more likely to adopt emotional strategies, although while educated mothers also seek solutions through reading and information gathering. Fathers generally adopt a pragmatic approach, on the other hand, they focus primarily on problem solving.

Furthermore, these parents are often deeply concerned and anxious about their child's future, which can significantly impact the quality of family life. They frequently worry about who will care for their child after they are gone, a concern that makes the present difficult to endure and the future daunting. Under these circumstances, parents tend to focus primarily on a single responsibility: ensuring their child with a disability achieves financial independence.

Regarding the search for information, several studies have highlighted parents' need for information about autism as soon as the diagnosis is announced. Among the parents we saw for consultation, they requested either the general practitioner or the pediatrician, who are often unable to provide many explanations due to their limited knowledge of pervasive developmental disorders, in order to alleviate their concerns.

In addition, some well-educated parents conduct research on the internet, often expressing difficulty in judging the relevance of the information available and in navigating the multitude of resources. Other parents attempt to join parent associations to compensate for the lack of information, with some becoming better informed about available treatments. However, most parents express a desire to share their experiences with others facing the same challenges in order to gain a better understanding of autism. Few parents show no curiosity about information, which suggests a sense of helplessness in the face of their specific educational situation.

3.3. Nature of the Marital Relationship

Regarding the nature of the marital relationship, we found that a child’s autism spectrum disorder can either strengthen and deepen the relationship or, conversely, place it under strain, create an increase in tension and aggression that can lead to a break-up. From the above, it can be said that the child's autism has an impact on the whole life of the family, mainly at relational, psychological and somatic levels. The families we work with function in an entangled way, i.e. there are boundary problems between the sub-systems: couple, parents and siblings, contrariwise the boundaries with the broader environment are rigid.

We will explore the psychological experience of the family, particularly the parents, and their reactions to the discovery of this disorder, which represents a significant trauma, drawing on a literature review and clinical interviews conducted with them; there were two main types of reaction among the Algerian families of autistic children, whom we interviewed:

- Families who are deeply concerned about their children and are willing to make significant efforts to address the challenges they face often seek guidance from practitioners to better support their child. These families remain open to personal change, show a readiness to put in the necessary effort, and manage feelings of guilt. They typically consult professionals to confirm or refute a diagnosis or to learn about care methods and available treatment options. After extensive research and consultations—often facilitated by referrals from doctors or recommendations from other parents of autistic children—these families tend to build strong relationships with therapists. However, in some cases, they may develop a degree of dependency or expresses aggressiveness and frustration toward the therapeutic team, reflecting their deep distress and need for support.
- The second category of families is rare but does exist: hostile, contemptuous, or indifferent families. This type of family sometimes reflects the seriousness of family dysfunction, the rigidity of their behaviors and attitudes, and parenting disorders or even parenting dysfunctions. Very negative feelings can emerge, such as hatred and animosity, whereas these children have a great need for affection. Anything perceived or experienced as ‘bad’ in the family becomes a 'bad object' in the Kleinian sense, and must be ‘expelled,’ ‘rejected,’ to the outside or even ‘destroyed.’ These families tend to resist and generally refuse any psychological help offered; they want to place their child in a care facility for permanent care, they try by all means. These families are either absent or only come for consultations when they are overwhelmed by the severity of symptoms, such as agitation or aggression.

> It is important to note that in our clinical practice, we have encountered families who have confined their child for 15 to 20 years. The children seen in our usual consultations have often exhibited behaviors characteristic of profound distress, some showing significant difficulties in responding to reality.

Also, for many parents, daily tasks are a significant source of stress, as are the chronic nature of the disorder, the limited communication with their autistic child, the lack of support from care services, the absence of time for vacations, and a very restricted social life.

To cope with their child's behavioral difficulties, some parents prefer to structure and organize their daily lives as much as possible, planning activities in advance to better control and avoid situations that may trigger crises. Some Algerian families have found themselves compelled to reconsider their entire way of life in order to adapt to their child's disorder. For instance, the B family chose to return to Algeria after several years of residing in a Gulf country, in search of a treatment center, a decision that impacted the father's employment and the family's overall lifestyle. Other parents prefer to live day by day, addressing problems as they arise. Consequently, the situation of disability can, in some ways, act as a magnifying mirror of the division of parental roles between the father and the mother (Philip, 2004).

3.4. Quality of Life for Siblings

The lives of siblings are also significantly impacted by this disease, their education, friendships, leisure activities, as well as their physical and mental health, are affected, At times, their suffering becomes visible, rendering them vulnerable in the eyes of other.

The authors further report that the emotions most frequently experienced by siblings include shame and jealousy. Some siblings cope by distancing themselves from the autistic child or displaying aggressive behaviors. Hutton and Caron (2005) also noted, in their study of families with a child diagnosed with autism, feelings of jealousy and hostility from siblings toward the child with autism (Cappe, 2009, p.223). In addition, some parents have observed that their typically developing children often experience sadness, and sometimes intense fear, in relation to their autistic brother or sister.

On the other hand, in some cases, positive family dynamics emerge, with many children exhibiting remarkable maturity and heightened sensitivity. They often display early solidarity, an increased sense of responsibility, resourcefulness, tolerance, and an unusual level of relational maturity for their age. These children may identify with their parents by adopting a protective and anxious attitude toward the future or even assuming a care-giving role toward the sibling with the disorder (Boussafsaf & Metz, 2024, p. 111). In some instances, this can result in ‘parentification’—a reversal of parent/child roles—where the child or adolescent is compelled to act as a parent toward their own parents or siblings. Moreover, parents observed that when the autistic child is younger, sibling relationships tend to be more positive

Therefore, the quality of sibling relationships is influenced by the level of marital stress. When parents experience fewer difficulties in their relationship, siblings are more likely to behave positively, demonstrating understanding and support for their brother or sister with the disorder. Conversely, when marital stress is high, children are more likely to exhibit negative behaviors, such as aggression and avoidance. The role of social support cannot be overlooked, as it reduces stress in parents and also influences the siblings. However, when the couple receives limited social support, sibling relationships tend to deteriorate, and will display negative behaviors toward the autistic sibling are more likely to occur. However, some parents express concerns and anxiety about the future dynamics within the sibling relationships.

Several authors (Scelles, 1997; Fisman, Wolf, Ellison, and Freeman, 2000; Wintgens and Hayez, 2005) emphasize the importance of involving siblings in the care of children with autism, taking into account their presence and specific needs (Cappe,2009,p.225).

4. Autism in Algeria: Reality and Prospects

In Algeria, this situation is both alarming and complex, as in addition to the marginalization of autistic individuals, there is a glaring shortage of appropriate structures to care for them. The number of these centers remains very limited, despite efforts by authorities to train psychiatrists, nurses, and psychologists to provide care. Additionally, child psychiatric consultations and the creation of specialized centers in both the public sector and through associations have been initiated.

A second challenge, highlighted by Ms. S. Bouarioua, Secretary-General of the Autism Association of Algiers, is the difficulty in diagnosing autism. This poses a considerable challenge for parents, who often lack information and access to qualified professionals when their child is diagnosed with autism or another disability. In this context, another issue arises concerning the schooling of these children, as they require support from specialized aides, which is currently lacking in Algeria. The integration of children with autism, who do not exhibit severe symptoms, into mainstream classrooms with accompanying aides is a measure that is being gradually implemented, albeit with significant challenges.

In Algeria, despite the challenges faced by parents, there has been significant progress in care in recent years. Autism is increasingly discussed in the media, specialized centers are being planned or have already been established, and parents are becoming more proactive. Training programs are being organized for professionals, including psychologists and educators, to better equip them to work with children with autism.

It is worth noting that a national autism treatment plan was launched in (2010) by the Ministry of Solidarity. This plan focuses on management, support, awareness-raising, and the specialized training of professionals. The Ministry of Health has also initiated training programs for doctors, psychologists, and psychomotor therapists to better respond to the needs of children with autism.

Day hospitals and outpatient clinics are being established, despite ongoing difficulties related to insufficient training and resources. In Algeria, the Population Directorate of the Ministry of Health reported in July 2021 that approximately 450,000 individuals with autism spectrum disorder (ASD) are currently receiving care in public and private medical and institutional settings, out of an estimated 12,000 school-age children with autism in the country (State of Autism in Algeria, 2021; Achachera & Levier, 2025, p. 115).

The national approach to the care of children with ASD is framed by the National Autism Plan 2024–2029, an intersectoral strategy structured around four main axes, designed to organize and strengthen the State's response to autism spectrum disorders. According to estimates published on the Autisme Algérie website (Autisme Algérie, n.d.), approximately one in every 150 children in Algeria is affected.

The first axis of the plan focuses on improving care, particularly through early screening, medico-psychosocial support, the implementation of individualized therapeutic projects, and the continuity of follow-up from childhood to adulthood. The second axis addresses the training of professionals to ensure appropriate detection and guidance by strengthening skills both in higher education and through continuing professional development. The third axis aims to support families and raise societal awareness through the development of informational tools, training parents to assist their children, and combating stigmatization.

The fourth axis promotes scientific research, particularly by improving national data collection and expanding knowledge about autism (Autisme Algérie, n.d.).

Therefore, the establishment of these specialized structures could facilitate comprehensive care encompassing educational, psychological, and medical dimensions.

5.Conclusion

This analysis of the literature and the presentation of practical data show that family life is profoundly disrupted by autism in its various forms, including Kanner's syndrome, Asperger's syndrome, and atypical autism. Organizing daily life with a child who has a pervasive developmental disorder is challenging. Indeed, the process of diagnosing and then establishing specialized care for the child demands significant time and energy from parents, often requiring personal sacrifices. The complexity of family relationships, friendships, social interactions, as well as professional and leisure activities, is also often highlighted.

However, our study is qualitative, and its results cannot be generalized, as it is limited by the exploration of a small study population. Nevertheless, it remains a valuable contribution to understanding this complex phenomenon.

Parental involvement is crucial in care, they need to be educated, informed, and supported. Addressing their suffering, as well as that of their other children, often necessitates family therapy. This approach aims to alleviate suffering and enable the family system to function more positively, facilitating communication, reallocating roles and responsibilities, and relieving parents of feelings of shame and guilt. In essence, the goal is to assist parents in accepting and managing the challenges they face, allowing them to invest in the future. In this case, organizing family group sessions can provide an opportunity to share experiences, foster strong bonds, release emotional energy, and offer mutual support. The Psychologists may suggest that parents consider having additional children if their first child has autism to prevent social isolation.

The adaptation or readjustment of environments, spaces, and relationships to meet the unique needs of the disorder depends not only on the efforts of parents or families but also on social and healthcare authorities.

While parents have made every effort to adapt, care organizations and stakeholders must reassess the functioning of institutions and the training of professionals to ensure they are capable of meeting the needs for care and adequate support.

In other words, individuals with autism and their associated behaviors surpass the coping abilities of their families. These families have, in turn, advocated for organizations to reshape their structures and ways of functioning to address their demands. This advocacy has mobilized the Algerian authorities, leading to the creation of care centers specifically designed for children with autism. Additionally, training initiatives for healthcare workers and the formation of associations have been established to support a population that faces not only the challenges of the disorder but also marginalization and neglect.

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