

Emotions and Needs in Parents and Children with Neurodevelopmental Disorders: The Integrated Therapeutic Intervention

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Abstract

Autism is a neurodevelopmental disorder mainly involving language and communication, social interaction, restricted, stereotyped interests, and repetitive behaviors.

Autistic Disorder is the most severe end of a group of neurodevelopmental disorders called autism spectrum disorders (ASD), which share the common characteristic of dysfunctional social interaction.

ASDs include several clinical conditions, defined by the Diagnostic and Statistical Manual of Mental Disorders (DSM V), namely pervasive developmental disorder, autistic disorder, and Asperger's Syndrome.

The aim of this review is to analyze the typical characteristics of Autism Spectrum Disorder, paying attention not only to the clinical aspects but also to the emotional experience of parents and children with ASD and evaluating the current integrated interventions used, for a better quality of life for parents and the whole family.

Keywords: neurodevelopmental disorders, autism, emotions and family needs, integrated treatments in autism.

Autism spectrum disorders: historical review

The term "autism" originated by Swiss psychiatrist Eugene Bleuler (1911) in order to describe a particular behavior found in adult subjects with schizophrenia who manifested a state of extreme isolation, and detached from external reality.

In 1943, the Anglo-Saxon psychiatrist Leo Kanner published a study of eleven children, in which he described childhood autism as a condition characterized by severe difficulties in affective contacts and social interactions; this definition represented an important step in the understanding of autism, as it focused on symptoms manifested during childhood.

Another important contribution, came in 1944, thanks to Austrian pediatrician Hans Asperger, who conducted a study of a group of children with obvious problems in socialization in addition to poor empathy and difficulties in motor coordination. This condition, called *Asperger's Syndrome*, was distinguished by the presence of relatively preserved language skills and less marked difficulties in affective contact than the disorder described by Kanner.

Further development on the concept of autism, occurred in 1980, when the third edition of the DSM (Diagnostic and Statistical Manual of Mental Disorders) officially recognized childhood autism as a separate diagnostic category by defining it through 6 main diagnostic criteria (which

included difficulty in social interaction, rudimentary language and resistance to change).

In 1992, Asperger's Syndrome was recognized as an independent diagnostic category, becoming part of the DSM. Its recognition reflected the growing understanding of the different manifestations of autism.

In 1994, the fourth edition of the DSM, further expanded the classification of disorders, establishing specific diagnostic criteria for Autism, Asperger's Syndrome and pervasive developmental disorders not otherwise specified. The goal was to provide a more detailed classification of the various forms of Autism.

In 2013, the new edition of the manual, introduced the category of "Autism Spectrum Disorders," which incorporated the different forms of Autism, previously classified separately. This restructuring reflected a more integrated and consistent approach to diagnosing and understanding the disorder.

Developmental autism spectrum disorders: definitions and classifications

Autism Spectrum Disorders (ASDs) belong to the macrocategory of Neurodevelopmental Disorders: a set of alterations that occur early and affect neurodevelopment,

causing social, personal, scholastic, cognitive, and emotional dysfunction in the individual who carries them (1).

They occur by age three with persistence into adulthood; diagnosis is possible at any stage of life. The deficits present in Neurodevelopmental Disorders are variable and may involve limitations in learning or control of executive functions, with global impairment of cognitive and/or social skills.

Part of the diagnostic category of Neurodevelopmental Disorders are the diagnoses of:

1. Intellectual disabilities;
2. Communication disorders;
3. Autism spectrum disorder;
4. Attention-deficit/hyperactivity disorder (ADHD);
5. Specific Learning Disorders (SLD);
6. Movement disorders.

The most common are Autism Spectrum Disorders and Attention Deficit/Hyperactivity Disorder. The disorders may occur in comorbidity, with other disorders, for example, an intellectual disability.

Autism spectrum disorders (ASD) are characterized by (1):

1. *Socio-communicative deficit:* Persistent deficit in communication and social interaction skills. This may include nonverbal behaviors such as eye gaze and gestures, or verbal behaviors such as stereotyped speech, delayed echolalia, repetitive questions, and verbal rituals.
2. *Pattern of repetitive behaviors and restricted interests:* Presence of repetitive and restricted behaviors within a restricted area of interests and activities, characterized by stereotyped use of objects and unusual responses to sensory stimuli.

They are part of a broad spectrum of conditions, part of a single diagnostic category, with different levels of severity and clinical manifestations.

Autism Spectrum Disorders include:

1. The pervasive developmental disorder.
2. Autistic disorder.
3. Asperger's syndrome.
4. Rett's syndrome.
5. Childhood disintegrative disorder.
6. The pervasive developmental disorder not otherwise specified.

The DSM-5 classification system (5) requires delineating different developmental pathways based on severity, verbal abilities, cognitive level, gene expressiveness, and therapeutic interventions used.

Basic psychic functions-sensory perception, attention, intellectual functioning, and social adaptation-may be impaired.

In order to make a diagnosis of Autism Spectrum Disorder, it is necessary to indicate the possible presence or absence of intellectual disabilities, language problems, medical, genetic alterations, and environmental factors, as well as possible mental, behavioral, or neurodevelopmental disorders, including catatonia.

The most common initial symptoms include a language delay, poor socialization, lack of social interaction, and atypical modes of communication.

Children with autism have a particular tendency to avoid eye contact, and their body attitudes and facial expressions have little connection to interpersonal interactions, show difficulty developing relationships and interactions with peers, and inability to share their emotions. There may be an absence of language and sometimes, this may be stereotyped and repetitive. Typical behavior is characterized by rituals, mannerisms and a special interest in inanimate objects; play often has unusual characteristics.

Although acting seemingly congruently, the child fails to understand the other's mental dimension and share his or her emotional states.

Three forms can be distinguished in autism spectrum disorders, divided according to the level of support required (1):

1. Level 1 (requesting support): requesting help to communicate; difficulty taking initiative in social interaction; atypical or inappropriate responses to the other person's requests; rigid behavior that interferes with functioning in different contexts; difficulty switching between activities and organizing and planning for autonomy.
2. Level 2 (requiring consistent support): major deficits in verbal and nonverbal communication skills; limited initiatives in social interaction; reduced or abnormal responses to each other's requests.
3. Level 3 (requiring very substantial support): severe deficit in verbal and nonverbal communication skills; minimal responsiveness to each other's requests; rigid and repetitive behavior; difficulty directing attention and changing point of interest.

This classification improves the identification of types of therapeutic treatment by taking into account the specific needs of the patient.

Autism spectrum disorders: nosographic framework

The symptoms of Autism Spectrum Disorders have two main characteristics: *persistent deficits in communication and social interaction in a variety of contexts* (criterion A) and *limited and repetitive activities and interests* (criterion B).

The first symptoms, concern non-social areas (e.g., motor development); those inherent in the social-communicative domain, may be evident as early as the first months of life. The child tends not to respond to his or her own name, eye contact is almost completely absent, they do not develop lallazione, nor actions aimed at communication (e.g., pointing, greeting and showing objects).

Despite this, the actual possibility of diagnosis may not occur until 2-3 years at the earliest.

The causes of autism are still being studied; the genetic origin is supported by several elements, including the higher risk of recurrence in families with an affected member and the higher frequency in males. However, only a small percentage of cases can be attributed to specific genetic

mutations. According to a major study, genetic factors contribute only 50 percent to the development of autism spectrum disorder, while the remaining 50 percent would be attributable to environmental factors. Environmental factors are not, in any case, specific and involve exposures to teratogenic factors prenatally, complications during the time of delivery, or postnatally (2).

Autism from a genetic perspective is associated with changes in brain connectivity during development, affecting the maturation of neural structures and leading to disconnections in neural networks, which may manifest as hypoconnectivity or hyperconnectivity. Recent studies have identified more than 100 genes that increase the risk of developing Autism Spectrum Disorders, with genetic mutations and copy number variants (CNVs) linked to these disorders.

Familial recurrence and twin studies have been instrumental in demonstrating the strong influence of hereditary factors in ASDs; however, they have also indicated its genetic complexity. The presence of genetic heterogeneity is also indicated by the fact that in a minority of cases (<10%) ASDs are associated with diseases caused by a single gene, including fragile X syndrome, tuberous sclerosis, neurofibromatosis, or various chromosomal abnormalities (3).

To obtain a diagnosis of autism spectrum disorder, the following diagnostic criteria (DSM-V) must be met (4):

- A. Persistent deficits in social communication and social interaction in different contexts (in current condition and/or history), not explainable by generalized developmental delay, and manifested by all 3 of the following:
 1. Deficit in social-emotional reciprocity ranging from abnormal social approach and inability to converse (bump and grind) to reduced sharing of interests, emotions, affectivity to total lack of initiative or response in social interaction.
 2. Deficits in nonverbal communicative behaviors present in social interaction ranging from poor integration of verbal and nonverbal communication, abnormalities in eye contact and body language, or deficits in the understanding and use of communicative gestures to a total lack of facial expressiveness.
 3. Deficits in initiating and maintaining relationships, developmentally appropriate (not including those with parents and caregivers) ranging from difficulties in adapting behavior to different social contexts to difficulties in sharing imaginative play and making friends to an apparent lack of interest in peers.
- B. Pattern of restricted and repetitive behaviors, interests, or activities as manifested by at least 2 of the following (in current condition and/or history, examples are illustrative, not exhaustive):
 1. Language, motor movements or use of objects in a stereotyped or repetitive manner (such as simple motor stereotypies, alignment or rotation of objects, echolalia, idiosyncratic phrases).
 2. "Sameness," inflexible adherence to routine, ritualized verbal or nonverbal behaviors (excessive reactions of intolerance to the slightest changes, difficulty in

transitions, rigidity in thought pattern, rituals of recurring questions, insistence on taking the same route or eating the same food).

3. Extremely narrow and fixed interests, abnormal in intensity or theme (e.g., strong attachment to or interest in unusual objects, excessively circumscribed and persistent interests).
 4. Hyper- or Hypo-reactivity to sensory stimuli or unusual interests in sensory aspects of the environment (e.g., apparent indifference to heat/cold/pain, avoidance response to sounds or materials of a specific texture, excessive sniffing or touching of objects, attraction to lights or moving objects).
- C. Symptoms must be present in early childhood (but may become fully manifest only when social demands exceed the limited skills possessed, or symptoms may be masked by learned strategies).
 - D. The set of symptoms involves clinically significant impairment in social, occupational, and general daily functioning.
 - E. These Symptoms are not attributable to an Intellectual Disability (Intellectual Developmental Disorder) or a Global Developmental Delay.

Individuals who present with significant difficulties in social communication, but whose symptoms do not meet the criteria for Autism Spectrum Disorder, should be evaluated for possible *Social Communication Disorder* (Pragmatic).

Cases of comorbidity are often found in children with medical conditions such as epilepsy, sleep disorders, gastrointestinal disorders, autoimmune disorders, and intellectual disabilities.

In addition, comorbidity with attention deficit hyperactivity disorder (ADHD) has been found.

Although ADHD and ASD present different issues, these two conditions share some features that make them sometimes problematic to distinguish. For example, attention deficits and interaction difficulties are common to the two disorders; both syndromes are associated with language and motor deficits in addition to mood and sleep disorders. There is an estimated 30 percent comorbidity among ADHD individuals among patients with ASD of skills and in the use of strategies necessary for the individual's well-being (5).

International Classification of Diseases ICD-10

The ICD (International Classification of Diseases) classification is a standardized system that categorizes diseases and related problems, it was developed by the World Health Organization (WHO). Currently in use is the 10th edition, which came into force in 1994 and was signed by 43 nations.

Autism Spectrum Disorders are classified in ICD10 under code F84.

It recognizes that the onset of ASDs is both influenced by a combination of genetic (both familial and sporadic) and environmental (e.g., perinatal causes) factors, all of which contribute to decree considerable variability in the manifestations of the disorder.

The disorder has been recognized to have a prenatal origin. Early diagnosis is possible with classification systems such as ICD-10, which is based on the presence of deficits in the behavioral triad: sociality, language, and stereotypic behaviors. However, because these deficits become evident only when the child reaches the age when language and social skills typically develop, diagnosis is often delayed.

WHO's ICD-10 was translated and published in Italy somewhat earlier than the official Ministry of Health version. This led to differences in the terms used. For example, code F84 was translated as *Comprehensive Developmental Disorders of Psychological Development*, while in practice *Pervasive Developmental Disorders* was used.

Differences between classifications and translations have caused inconsistencies in diagnoses, depending on the manual used. ICD-10 includes several disorders under the code F84, such as childhood autism (F84.0), atypical autism (F84.1), Asperger's syndrome (F84.5) and others; this makes this classification is overly broad and, consequently, unspecific.

International Classification of Functioning Disabilities and Health ICF

In recent years, the study of disabilities has called for the use of languages and tools capable of addressing the complex issues that these conditions present to rehabilitation and socioeducational professionals. *Language expresses the culture of a society, and is indicative of the attitudes held within it with respect to specific problems, and thus also with respect to disabilities.* The use of new languages, consonant with the needs of people, must express a different way of conceiving the difficulties of human beings, where disability and handicap must be considered as a complex set of conditions, many of which are produced and reinforced within the social environment to which they belong, and must no longer be seen as problems of the individual person or worse still, negative attributes or distinguishing features.

In 2001, WHO provided practitioners with a new tool: the International Classification of Functioning, Disability and Health (ICF), this, deals with the description of functioning and disability in relation to health and environment. This instrument has innovative features in terms of both language and what defines disabilities. Indeed, there is a need to use standardized and shared language not only in clinical settings but also in the educational sector. ICD-10 provides a classification of medical diagnoses, useful for epidemiology, health management and clinical research the ICF promotes a broader, multidimensional perspective, assessing how health conditions affect people's functioning and participation in social life.

The ICF, employs the biopsychosocial model, integrating the medical approach of ICD-10 with a social model of disability, allowing not only medical conditions but also their consequences on people's quality of life and social participation to be assessed.

WHO recommends the joint use of the two classifications to obtain an integrated and comprehensive view of the health of individuals (6).

The ICF uses an alphanumeric coding system to classify various aspects of health and functioning. The major components are labeled by letters: *b* for body functions, *s* for body structures, *d* for activity and participation, and *e* for environmental factors. Each chapter is divided into subchapters that allow detailed classification.

Alphanumeric codes are followed by qualifiers indicating severity of impairment, nature of change, and location. Activities and participation are assessed with two qualifiers: "performance" (what the person does in the current environment) and "ability" (what he or she could do in a standardized setting). The difference between these two qualifiers helps identify the influence of environmental factors. They are coded to indicate whether they are a barrier or a facilitator.

The ICF checklist is used to describe the health condition of the past 30 days, which allows for the entry of biographical data and diagnosis according to ICD-10 and details the health status.

The ICF is a key reference, as it allows a heterogeneous set of information on health status to be translated into components, codes and qualifiers, proving to be an appropriate, sharable, monitorable, sustainable and compatible tool with other existing systems (7).

Autism and the family system

The family is considered an open system in constant interaction with the external environment, where the change of one of its members affects the others and the entire family system. In a family system, communication is a dynamic process, and every action is both cause and effect of a continuous process of mutual influences.

Families are stable and maintain stability and balance through self-regulating mechanisms that allow them to cope with moments of crisis while maintaining their cohesion and identity, minimizing deviations from their state of equilibrium. Families also possess the ability to evolve and adapt to new situations, which allows them to develop new levels of organization and functioning, overcoming old dynamics. Family therapy, aims to promote such processes of change.

According to the developmental approach, families with an autistic child begin to differentiate from birth, when challenges emerge related to perception and acceptance of the disorder, as well as caregiving tasks and couple reorganization. Many studies show an association between the presence of autistic symptomatology and parental stress (8).

One of the main stressors is lack of interaction; families may experience deep distress due to lack of knowledge of the child they are raising, and of themselves as parents, failure of intuitive behaviors, dealing with a diagnosis that has shattered expectations, the need to find a new family balance, and confrontation with other parents. Referring to

Erikson's model, the stages of the individual life cycle are distinguished by 8 stages and each developmental stage turns out to be characterized by a specific problematic situation, which requires a reorganization of family relationships to be overcome. Overcoming it will lead to the next stage through the skills developed in the previous one. According to the life cycle perspective, moments of family crisis play a positive role because -although they create distress they represent an opportunity to trigger developmental processes. The situation becomes problematic, the moment the family fails to adapt and respond to the critical event by establishing new relational modes, appropriate to the new needs.

Critical events characterizing the stages of the life cycle are classified into two categories: predictable and unpredictable. The former, mark the succession of stages in the family cycle, involve situations that most people and families expect to encounter during their lifetime (marriage, child birth, raising children, adolescence, death of aging parents, etc.). *Unforeseeable* critical events, are unexpected situations, such as, the birth of a child with Autism Spectrum Disorder.

These events result in increased stress, as they are unexpected and are in addition to the normative critical events already anticipated in the developmental stage the family is in. These events, require reorganization within the family system and additional resources to overcome. Stress, primarily affects parents of children with autism, siblings also play a significant role. A positive sibling relationship can provide important social support for children, associated with fewer behavioral problems, loneliness, and higher self-esteem (9).

The studies by Sanders and Morgan in 1997, highlighted how typical behaviors of children with autism can jeopardize the quality of sibling relationships (10), focus on the negative effects in typically developing children who have siblings with autism, such as loneliness, annoyance with sibling behaviors, internalizing and externalizing problems, attention disorders, depression, lower social reciprocity and relational difficulties with the peer group. The lack of reciprocity in conversation and the possible absence of language hinder intimate exchanges between siblings. According to further studies documented, siblings of autistic children show greater tolerance, but also greater embarrassment and fear of social judgment (11).

Growing up, siblings may worry about the future, fearing that they will not be able to take care of their sibling. However, as mentioned, there are also positive effects of having an autistic sibling. Some studies show sibling relationships characterized by less conflict and competitiveness and more admiration for autistic siblings (12).

In addition, it has been shown that siblings with typical development feel a sense of pride in their ability to teach younger siblings with autism.

For autistic children, siblings are a significant social reference and tend to value their relationship positively.

The communication of the diagnosis

The diagnostic process is for families, difficult and stressful. Parents demand quick answers regarding their child's problems, but clinicians may have doubts, about the nature of the disorder. Numerous studies report dissatisfaction regarding the diagnosis received when parents first seek help (13).

Diagnosis requires *clarity and gradualness in communication*. The main issues reported by parents of children with ASD include pediatricians' lack of knowledge of the condition, inadequate diagnostic communication, and lack of detailed information on etiology, characteristics of the syndrome, opportunities for services, available interventions, and rights and benefits for the person with a disability and his or her family.

As parents age, caregiving concerns increase and the issue of their child's future after their death becomes central.

The *Family Stress and Coping Theory* model highlights, the difficulties and steps necessary in order to overcome the crisis related to the perceived disorder.

The model identifies crisis as a time of transition leading to a new family adjustment, which can be positive or negative. The resources available to address critical events are both material (socioeconomic, income, education) and relational (cohesion, communication, adaptability, couple support). Developing individualized school and work inclusion programs can make a difference in improving the quality of life for people with autism and their families.

Parenting a child with ASD.

The birth of a child with autism is an event that creates a crisis in the family system, disorienting the family in a very pronounced way, procuring a high level of initial stress, from which a crisis may originate that requires a renewal of previously achieved balances. The behavior of the autistic child, hinders the development of fruitful relationships, creating difficulties for the parents. Very often, the autistic child's behaviors are misunderstood, with inevitable guilt and inadequacy in the parents. During this early stage, they, while hopeful and motivated to support their child, face numerous challenges. However, sharing even small successes in a peaceful environment can help improve the relationship between the child and parents. This strengthens mutual trust and individual capabilities, promoting a better quality of life for all family members. As pointed out by Minuchin (14), *the family is the first social context in which the child grows up*; therefore, integration in the family environment is the first educational goal for a child with autism.

The developmental stages of a family with autistic children are characterized by critical events and complex developmental crises, which deeply affect all family members. Problematic behaviors, such as destructive, violent conduct, inappropriate sexual expression, eating and sleeping problems, are a significant source of tension for parents. Destructive conduct in public places can generate embarrassment, while violent conduct becomes more difficult to manage during adolescence, when children gain more physical strength.

Families of individuals with autism often struggle to lead normal lives and constantly live in anguish because of uncertainty about the future. Social and medical interventions, which last for many years, and the absence of effective treatment mean that families have to care for their child for a long time. Fear of the consequences of problem behaviors can lead parents to socially isolate themselves.

In the family, the main caregiver is often the mother. This role frequently leads them to experience a feeling of "wounded motherhood." Mothers are more likely to be ashamed of their child's problems and their identity is threatened by their child's disability or illness as a mother's perception of her own caregiving significantly influences how she defines herself and the meaning of her life (15).

When the child, while growing physically, does not develop a corresponding level of intellectual maturity, "maternal care" is placed in a semireal situation that can present serious psycho-emotional difficulties, and risks of conflict and dissociation (16).

Not all mothers are able to overcome these difficulties, which can lead to maladaptive reactions. Guilt is often exaggerated, both toward themselves and others, including spouses and their families of origin.

The search for a 'culprit' can crystallize the situation and intensify pre-existing conflicts, preventing the planning of an adequate life project. If the initial pain is not overcome, the relationship with the child may deteriorate, manifesting in attitudes of denial, such as the incessant search for definitive solutions through specialists. At the opposite extreme, an overprotective attitude may prevent the child from growing independently. The sense of failure and inadequacy experienced in mothering tasks can slowly mature into a state of inadequacy even in the face of wifely tasks and a maladjustment to the social environment (17). Recently, scientific interest has also extended to the father figure. Fathers seem to be less affected by their child's disability, both practically and psychologically, but they too experience "wounded fatherhood." They experience the effects of their children's autism mainly indirectly, through their wives' experience. The stress experienced by wives is perceived by men as disturbing the marital relationship and home life. Thus, the personal effect indicated by fathers as most disruptive is the threat to their marriage while their work career is only partially affected (17).

Usually, mothers are most affected by the psychological health of other family members, while fathers' stress is mainly associated with their child's problem behaviors.

Reactions to the diagnosis of autism and family restructuring

Parents' reactions to the diagnosis can give rise to feelings of frustration, stress, and disorientation, for there to be functional family well-being, it is essential for members to moderate negative feelings and implement a restructuring of the family unit. Acceptance of the diagnosis by both parents is necessary. *Acceptance and Commitment Therapy* (ACT), based on Hayes, Barnes-Holmes & Roche's *Relational Frame Theory* (RFT), has been shown to be particularly effective. ACT helps parents understand and

accept their own thoughts and feelings, without trying to change them; it teaches them to distance themselves from their thoughts through the technique of *cognitive defusion*, seeing them for what they really are; it encourages through *'acceptance'*, through conscious contact with one's own experience, dealing with psychological problems rather than trying to eliminate them as one would with a disturbing external factor.

Another crucial aspect of ACT is the emphasis on values and commitment to action; *one should not put one's life on hold while dealing with psychological problems*. ACT encourages parents to learn to live more consciously and meaningfully, improving individual and family well-being.

In addition to the therapeutic aspects, it is important to consider the practical impact of the ASD diagnosis on daily life. Families often have to reorganize their routines and adjust to the specific needs of the child, which may include participating in behavioral, occupational, and speech therapies. These adjustments can be a source of additional stress, but also an opportunity for the family to develop greater resilience and cohesion.

Types of family support

Taking into analysis the needs and difficulties of parents of children with Autism is the main point, for the design of appropriate educational support interventions. Support actions and guidance must be designed according to the impact they have on the entire family system. It is essential to support families in enhancing their adaptive capacities and, in particular, resilience in the face of the challenges posed by autism. *Providing ongoing psychological support to families is a must*. There is no question of leaving families alone, or of discontinuing the help provided in the early stages, as the journey is long and difficult and must be addressed together to ensure an acceptable quality of life (18). This need for support is one of the main reasons why parents seek comfort, support and help. One of the greatest difficulties in the growth and development journey of children and adults with Autism is the management of daily life, which is often characterized by significant difficulties in counteracting the problem behaviors peculiar to the disorder-it is essential that parents be informed and supported in their application, as the results may not be immediate.

The major needs of families are as follows:

1. Early diagnosis, communicated in understandable, non-technical terms;
2. An explanation of what autism is;
3. A good assessment to understand the level of the child's autism: what he/she can/can do and what/how he/she can learn;
4. The possibility of psychological support for caregivers of the person with autism and the need for responses that allow moments of support and "respite" for family members themselves;
5. The ability to access tools and opportunities for support in managing daily life, especially in dealing with "problem behaviors" (19).

Parents emphasize the need for help and quality educational interventions as a priority (20).

Assistance is manifested in the ease of finding and using information about Autism; in the availability of competent "speaking places" to engage with other families; and in the demand for financial and practical supports to move around the area and reach places of care and education.

The need for high quality and specialized interventions is a recurring theme. Parents require constantly updated specific expertise in the field of Autism, with special attention to the connection between the different actors involved in intervention projects.

Among the wishes expressed is a strong need for relief, the integration of their children into society, and the search for a normalcy that respects diversity (21).

Parents demand that their children participate in daily life, being integrated into a context that values individual differences as resources for the community. Although it can be difficult, sometimes almost impossible, to fully understand the interests of children with autism, it is crucial not to give up and to keep searching for answers. The main goal of parents is to see their children fulfilled in their interests, helping them build a life that is not simply suffered, but *actively lived*.

The issue of *family loneliness* and the burden it brings is closely related to the need for communication and accompaniment. Fragmentation of services is also a significant problem that can be addressed in an innovative way, avoiding traditional solutions.

An additional supportive approach, particularly effective in reducing stress and anxiety in mothers of children with Autism, is weekly training programs conducted by other mothers. These interventions, in addition to decreasing tension levels, have been shown to significantly improve mother-child interaction. The sessions, lasting an hour and a half each, are designed to engage volunteer mothers who wish to share experiences and gain useful tools for stress management.

One such program focuses on *mindfulness*, an attention training that encourages focusing on the present sensory experience, thus promoting mental well-being and anxiety reduction.

Another program is based on the principles of *positive psychology*, and aims to explain how guilt and worry can be dysfunctional, and in addition to developing one's character strengths. This approach includes mental exercises centered on concepts such as gratitude, forgiveness and optimism, thus helping to build a more resilient and positive mindset in mothers.

The integration of such interventions into the family support system expands the options available to families with children with autism, offering not only practical support but also psychological and emotional tools that can improve the quality of daily life. These programs, through the active involvement of mothers, strengthen the community support network and promote a healthier and more collaborative

family environment in which the well-being of each member is valued and supported in an integrated way.

Programs and intervention for children with Autism Spectrum Disorder.

The importance of early intervention is well established, there are significant differences in access and types of treatment received, a study of 1,680 parents in 18 European countries found that 91% of children with ASD aged 7 years or younger received at least one type of intervention, either language therapies, behavioral or developmental interventions. Developmental approaches are based on developmental theories such as attachment theory and emphasize the importance of a critical period for the acquisition of essential skills, setting specific goals for each child (22).

These approaches, are based on meaningful relationships and active interaction of the child in therapy, using the technique of *play* to stimulate spontaneity and motivation. In recent years, the early identification of Autism Spectrum Disorders has made it possible to plan more effective psychoeducational interventions for preschoolers. A 2011 review highlighted the importance of interventions aimed at joint attention and communication, although less than half promoted the child's internal motivation, underscoring the need for further studies to clarify the effectiveness of these approaches (23).

It is essential that caregivers of children with ASD understand that although there are no universal solution cures, appropriate educational approaches can make a big difference. Among the most studied and applied methods are: applied Behavior Analysis (ABA) and Discrete Trial Training (DTT), which breaks down the skills to be learned into simpler units, teaching them one at a time with the help of reinforcement. However, this intervention was found to have various limitations, such as the lack of spontaneity in the treated children; hence, the need to develop integrated methods that also enhance social relationships.

The guidelines of scientific societies indicate some basic principles for effective interventions (24):

1. They must be evidence-based, recognizing the importance of rigorous studies to support their effectiveness;
2. They must be early, intervening as early as the second year of life to support communication and interpersonal skills;
3. They must be intensive, extending to all contexts of the child's life;
4. They must actively involve parents, both in understanding the disorder and in participating in therapy.
5. It is necessary to consider not only the child, but also his or her context, to prevent situations such as bullying or misinterpretation of behavior in environments such as school.

The main educational and rehabilitative intervention programs.

Autism programs and interventions, have been developed to support and promote the progress and well-being of children.

There are different approaches, varying in methodology and goals, but *all aim to improve social, communication and behavioral skills*. Below are some of the main educational and rehabilitative intervention programs in children with ASD:

- The *DIR - Developmental Individual-Differences, Relationship-Model* - developed by Stanley Greenspan and Serena Weider, which is an innovative approach designed to understand and promote positive development in children with Autism Spectrum Disorder. This model focuses on the six developmental stages identified by Greenspan, each of which is crucial to a child's emotional and behavioral growth. At the point when one of these stages is not adequately developed, issues such as regulation disorders and/or disorganized emotional responses may emerge.

A practical application of the DIR model is the *DIR/Floortime*, which emphasizes individual interaction between child and caregiver through play and daily activities (25).

This approach has shown promising results for preschool children with ASD, although further research is needed to confirm its effectiveness on a large scale.

- The *JASPER model - Joint Attention, Symbolic Play, Engagement & Regulation* - developed by Connie Kasari, focuses on skills fundamental to social communication, such as joint attention, symbolic play and imitation. The intervention, which involves a combination of individual and group sessions, aims to enhance these fundamental skills in a structured and engaging context. This intervention has been shown to significantly improve the social, cognitive and language skills of children with ASD in both individual and group settings.
- The *Early Start Denver Model (ESDM) - Early Start Denver Model* - combines principles of *Applied Behavior Analysis (ABA)* with developmental and relational theories, aimed at improving symptoms in children with ASD from early childhood (this makes it useful for early intervention). The intervention takes place in the child's natural environment and involves sessions with trained therapists and parents. Current findings indicate that ESDM is able to reduce symptom severity and promote development (especially language).

A longitudinal investigation done on 39 6-year-old children with ASD confirmed improvements in typical autism symptoms and adaptive behavior, which persisted even two years after the intervention ended (26).

Another research, confirmed the effectiveness of ESDM compared with usual interventions, showing benefits for preschoolers with ASD.

A 2016 review indicated that although the results are promising, there are areas that need further investigation, such as sustainability and long-term effects (27).

However, it is crucial to continue exploring its long-term effectiveness and sustainability.

- *Milieu Teaching (MT)* aims to teach new communication skills in natural settings such as home or school. It emphasizes the use of social interactions and communication patterns to improve children's language and behavioral skills.

Several variants of this intervention have been shown to improve communication skills, but variability in the quality and consistency of application suggests the need for further studies to optimize results (28).

The *Preschool Autism Communication Trial (PACT)*, focuses on communication between parents and children with autism aged 2-5 years. This approach aims to improve parental sensitivity and responsiveness through *video-feedback* techniques. Early studies indicate that PACT can foster positive social communication strategies, and lead to improvements in both groups and the usual intervention. Research conducted in South Asia, India and Pakistan among 64 children aged 2-9 years confirmed positive results (29).

However, a more recent study of older children (8-12 years old) did not show a significant impact regarding stress reduction and increasing parental well-being (30).

Applied behavior analysis (ABA).

Applied Behavior Analysis (ABA) is a therapeutic approach derived from the school of behaviorism, a field of psychology that focuses on the study and modification of behavior through the application of scientific principles. This method has been recognized in the treatment of Autism Spectrum Disorders and other disabilities because of its ability to structure learning in a systematic and organized way, responding to the specific needs of children. ABA assumes that behaviors can be learned and improved, with *positive reinforcement*, rewarding desired behaviors to encourage their repetition. In the context of autism, ABA breaks down complex skills into smaller, manageable units that are taught progressively, following an order of increasing complexity. This method of teaching proceeds through steps, and is known as *task analysis*, as it allows more complex skills to be built from individual basic skills. A child who needs to learn to communicate might start by learning simple gestures, then move on to the formation of increasingly elaborate sentences. A key aspect is the '*highly individualized approach*'. Each intervention is designed with the child's individual characteristics and specific starting skills in mind. There is no universal model of intervention' but, rather, a set of strategies adaptable to each individual's needs. ABA a *flexible method* that can be applied in different settings, such as school or home, and be modified and optimized according to the child's progress and needs. One of the criticisms of the method is that this is prioritized on technique rather than the relationship with the child, in fact, in the ABA method approach the building of a meaningful relationship is central. Through specific techniques, such as *pairing*, therapists work to establish a positive connection with the child, which becomes the basis for effective intervention. The relationship is therefore not secondary, but a key element in the success of treatment. The effectiveness of ABA is supported by an extensive scientific literature.

Research has demonstrated the effectiveness of the **ABA method** in reducing dysfunctional behaviors and improving and increasing communication, learning and socially appropriate behaviors (U.S. Department Of Health and Human Services, 1999).

As mentioned earlier, Lovaas O.I (31) was the first to carry out targeted research on individuals with **autism**. It demonstrated the primacy of language training within the educational process and the greater likelihood of achieving normal functioning when the intervention was applied early and intensively (32). In the most important evaluative study about the validity of the behavioral approach on individuals with **autism**, Lovaas O.I (31) (1987) compared the progress of three groups of children with **autism**. The group (N=19) involved in an intensive (40 hours per week) and early behavioral treatment program for more than two years achieved significantly higher results on all standardized tests than the two control groups: one involved in a 10-hour per week program and one receiving the state standardized intervention. In addition, 47 percent of the experimental group achieved within normal results in all developmental areas and by age seven were integrated into "normal" classrooms without support.

McEachin J.J et al. (33) demonstrated how, in adolescence, eight of the nine children in the Lovaas O. I group continued to attend school without the need for support and were indistinguishable from peers.

One of the criticisms often leveled against Lovaas O.I.'s studies is that the effect on the experimental group was not due to the intervention itself, but rather to the intensity with which it was administered. In response to this criticism, Eikeseth S. et al. (34), compared two groups of children between the ages of four and seven: one involved in an intensive behavioral intervention (30 hours) and another in an eclectic intervention, i.e., an intervention consisting of several approaches (TEACCH, speech therapy, sensory therapy, occupational), but equally intensive (30 hours). The results statistically significantly favored the behavioral group in all areas of development and particularly those of expressive and receptive language.

Sallows , Gaupner in later research, replicated Lovaas O.I.'s findings, showing that about half of the children who underwent early and intensive behavioral intervention achieved normal levels of adaptive and intellectual functioning by the age of seven (35).

Simply using the **ABA method** is not sufficient to produce the desired results; to achieve significant improvements, it must be implemented with sufficient intensity (30 to 40 hours per week) (36,37,38). The intervention achieves better results when it is implemented for a longer duration. Children with **autism** who received early intensive behavioral intervention from two years of age and up achieved better treatment outcomes (35,37,39,40,41). The response to treatment appears to be significantly variable among different children. Therefore, several studies have tried to identify the characteristics of children that allow for better outcomes. Bono M.A. et al. found that intervention successes were correlated with participants'

initial language skills and their ability to respond to joint attention requests from others (42).

In school inclusion, ABA has proven to be particularly useful. Inclusion of students with disabilities in Italy was formally recognized in 1977, with Law 517, which abolished differential classes, allowing them to attend regular classes. Since then, Italian schools have sought to address the specific needs of students with Autism Spectrum Disorders, who often present difficulties in verbal language as well as in understanding nonverbal language and, consequently, in social interactions with peers and adults. These students may have difficulty with gaze sustaining, sharing objects or activities, preferring to work alone at their own pace.

Managing emotions and understanding the feelings of others, can be complicated for a child with an Autism Spectrum Disorder. It is essential, to build a school context that is welcoming and responsive to the needs of these pupils (43), promoting their *inclusion* and reducing the risk of *school and social isolation*. Interaction with peers provides opportunities for functional learning, understanding of social rules, and practical application of learning (43).

Studies show that ABA-based interventions lead to better results than other techniques and that the improvements achieved are often transferable to other life contexts. In addition, parents of children following this method generally report being satisfied, feeling more involved in educational decisions and better able to manage daily life (44).

Through structured teaching and a strong focus on the therapeutic relationship, ABA helps children develop fundamental skills, improving their quality of life and their ability to interact with the world around them.

The TEACHH method

The TEACCH method, developed by Schopler and coworkers from 1980 to 1991 (13), is an educational and individualized approach that focuses on developing the diverse abilities of the child with Autism, starting from his or her specific strengths, interests and needs.

This method aims to promote the highest degree of independence in the personal, social and work spheres of the individual, using educational strategies that enhance the skills of the person with autism. The model places special emphasis on visual learning, believing that children with autism can better understand information through visual perceptions, rather than auditory ones. For this reason, the TEACCH method is distinguished by the use of behavioral and developmental techniques implemented within a structured environment, following rigid daily schedules, made visible through the use of visuals. Such visualization not only defines the timing and phases of various activities, but is particularly useful for children with verbal difficulties or poor language skills, as the images can compensate for communication deficits and improve the quality of their lives. Structured teaching is critical in helping professionals understand children's needs and learning styles, facilitating their ability to visually process information, participate in daily activities, and attribute meaning to them.

The method is characterized by a strong *personalization of interventions*, tailored to the characteristics and needs of each individual. This flexible approach facilitates adaptation to each child's unique needs, but has made standardization of interventions difficult for large-scale scientific observations.

A key aspect of the TEACCH method is the use of visual tools to facilitate communication and understanding of daily activities. Among these tools are:

1. Day plans, which help make environments and activities predictable.
2. Task analysis, which breaks down complex behaviors into sequences of microbehaviors that are more easily learned,
3. Communication books, containing various pictures, which the person with autism may use mainly for everyday activities, such as requesting food or asking to be escorted to the bathroom.

The visual tools used vary according to the cognitive abilities of the subject, ranging from three-dimensional objects to photographs, drawings or simple pictograms Cassano A. (45). A key aspect is the involvement of parents as *co-therapists*, which makes it possible to implement the program at home as well.

Some authors have compared ABA and TEACCH treatment models applied to pupils with autism spectrum disorders, examining their comprehensiveness and validity: they concluded that there is insufficient reliable evidence to prefer one approach over the other, and that neither parents nor teachers show a clear preference for either (46).

However, it should be pointed out that both models have specific elements considered significant for the treatment of autism.

Another study compared the results of the TEACCH program with those obtained from children on the waiting list for treatment. In a randomized, controlled pilot study, eleven children with high-functioning autism, aged 5 to 6 years, were recruited along with their mothers (47).

The results showed that children assigned to the TEACCH program made greater progress than the control group. Recently, a variant of the program, FITT, has been developed that focuses on parent-mediated home intervention, showing positive effects on children's mental well-being and social communication, making it a viable option for families aiming for a more personalized, home-centered intervention. However, despite the promising results, further development and research is awaited to refine its key concepts (48).

The therapeutic role of the family.

In therapeutic interventions for children with Autism Spectrum Disorders, the role of the family is of crucial importance, and this is evidenced by experience in the therapeutic field and clinical research. Parents play a key role initially as observers, focusing on educational programs and behavior management, thus developing a deep knowledge regarding the child's abilities. Through appropriate support, this knowledge can become a useful

resource for possible therapeutic interventions. The main goal is to *inform* and *educate* parents; this will bring about family well-being, reducing the risk of depression or other issues related to parental stress due to the diagnosis, which will also benefit the child's quality of life. In order to create a collaborative environment, it is necessary for the practitioner to guide the parents and support them in the initial disorientation phase, introducing them to active participation by playing the role of *co-therapists*. *Parent Training* is a key intervention in this process. It focuses mainly on teaching parents specific techniques to manage their child's problem behaviors and foster their development. A 2015 study classified these interventions into two categories: *parent support programs* and *therapies where parents are directly involved* (49).

Parent Training, therefore, not only sees parents as active individuals, but helps them learn practical strategies that they can apply in everyday life. Research shows that parental involvement makes treatments more effective than when they are managed only by specialists, an example of which is *the Evidence base update for autism spectrum disorder* Smith T., Ladarola S. (50).

When parents apply what they have learned at home, they help maintain and consolidate the skills the child develops in therapy. Crucially, this support should continue over time, adapting to the child's growth stages. Summarizing what has been said so far, the inclusion of parents and family members in the educational program, accompanied by appropriate training, expands opportunities for intervention outside of specialized centers. This allows for improved interactions with the child and contributes to a smoother life course for the entire family.

Conclusions

Early intensive behavioral intervention is the only scientifically validated educational intervention for the rehabilitation of individuals with autism. However, the application of such an intervention is complex and requires no small amount of preparation on the part of practitioners and supervisors. The ultimate goal of behavioral intervention, whether short-term or long-term, is radical change in socially significant behaviors, and for some individuals, total and independent inclusion in the surrounding social community.

Autism is one of the areas in which the 'application of the principles of behavior analysis has proven most effective in bringing about long-term ameliorative changes, more so than any other type of educational intervention (51).

Based on the effectiveness of this type of program, we can conclude that the best results are obtained when the program is applied to children at an early age (beginning at about age 3 to 4 years), starting at 30 to 40 hours per week, for a minimum of 2 years, and initially within a one-to-one relationship with the practitioner.

The program should, in addition:

- 1) Address all deficit areas of each individual child, with clearly defined goals;
- 2) Address all problem behaviors manifested by the child;
- 3) Be based on the principles of learning and motivation;

- 4) Contain both components of DTT (discrete trial training) and NET (natural environment training) in an integrated manner;
 - 5) heavily involve the family, with parents actively participating in the implementation of the intervention;
 - 6) be initially home-based and gradually extended to other viewing contexts (e.g., school);
 - 7) be led by experts with postgraduate training and certification in ABA and experience in educational programming with people with autism (51).
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