A new decade for social changes
Autistic people's family and emotional intelligence

Irene Chaidi, Athanasios Drigas, Charalampos Karagiannidis

1Net Media Lab Mind-Brain R&D IIT, N.C.S.R. ‘Demokritos’, Athens / University of Thessaly, Department of Special Education, Volos, Greece, 2N.C.S.R. Demokritos, 3University of Thessaly /Department of Special Education, Volos, Greece

irhaidi@gmail.com¹, dr@iit.demokritos.gr², karagian@uth.gr³

Abstract. In recent years there has been a growing interest in people on the autism spectrum but also the impact it has on their families, both in terms of the cohesion and relationship that develops between its members and its emotional intelligence. The aim of this work is through the literature review a) to depict the emotional intelligence of families with a person on the autism spectrum b) to present the research findings c) to present the factors that affect the emotional intelligence of families.

Keywords. autism, family, emotional intelligence

1. Introduction

Autism Spectrum Disorder (ASD) is a disorder that affects people throughout their lives creating barriers to understanding exactly what they see, hear and generally feel so that they experience serious problems in social relationships, communication and their behavior and more generally in their socio-emotional interactions.

In recent years, diffuse developmental disorders have been an area of great research, clinical and social interest, both on the part of parents and health and education professionals [1]. The research interest is also focused on the parents, siblings and more generally on the family of people with autism as well as on the effectiveness of appropriate and timely therapeutic intervention and education of parents, as it is accepted that the family is a key factor in physical and mental development. The child's relationship with the family is two-way, the parents influence the child, which in turn influences the parents [2].

It is a fact that the family and especially the parents of autistic people go through a painful long journey through a series of stages of adjustment of emotional disorientation and emotional deregulation until they accept autism disorder.

2. Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder is a serious, widespread disorder of the development of the individual, accompanies it throughout life, and affects his perception, thinking and behavior and is characterized by: "a) significant difficulties in the development of social and communication skills and interactions. of the individual and those around him, and (b) limited and recurring stereotyped interests and behaviors. " [3], [4].
The diagnosis of ASD is made by comparing the individual's behaviors with the symptoms listed in the list of diagnostic criteria of its official organizations: American Psychiatric Association (APA) DSM-V (Diagnostic and Statistical Manual) and ICD-10 (International Classification) World Health Organization (WTO).

It should be noted that both the diagnostic criteria of the official Organizations and the description of the autism of the researchers follow the "Trinity of Social Interaction Disorders" of Wing: a) Communication disorder b) Lack of communication and c) Disorder of social understanding and imagination - lack social understanding and imagination [5], which categories according to the revised version 5 of the DSM (DSMV), were replaced by 2 groups: a) social communication and b) stereotyped, repetitive behaviors, activities and interests.

Also, people with ASD show great heterogeneity in terms of social disturbance, lack of motivation for interaction, which in some cases leads to the avoidance of interaction both tactile and visual contact, while others actively seek interaction, but either do not "show »Empathy or interact in a temperamentally repetitive way. People with ASD also appear to be deficient in their emotional organization so they have difficulty communicating and socializing with those around them and their family. [6].

3. Emotional Intelligence

[6] states that the individual coexists with logical and emotional intelligence as emotions play an important role in his life "because as the subjective response of the individual to the event that caused the emotion, they have the ability as an internal morality to guide us in making decisions , changes in behavior, facial expression and posture. "Scientists point out the importance of emotional intelligence in achieving personal and collective goals. They emphasize that most of the time, one's general intelligence does not guarantee success unless it is combined with a high degree of emotional intelligence."

The term intelligence has been defined and focuses mainly on the achievements of intellectual and not so much on what intelligence is [7], he points out "Cognitive intelligence defines what we can measure", while the scientific definition states: "intelligence is a complex and complex cognitive function, which includes many factors, including the ability to gain new experiences, adapt to new situations. and build on previous experience in dealing with new difficulties or problems "[8], [9].

From ancient times the emotion is defined as: "a function of the body, which either alone or in cooperation and interaction with mental functions contributes to the overall development of man and enhances his ability to adapt." [7], while in Psychology, the term emotion was used by Hume to describe passion or love, [10] for the first time in the mid-18th century, while modern theories such as Fredrickson's theory describe positive emotions [11], [12] but also in previous theories [13], [14], [15], "the term emotion expresses the multidimensional forms of the body's response to environmental challenges, which are manifested at various levels, such as expressive, cognitive, neurological, normal or biological, etc. " and is accepted today by most scholars-researchers who deal with emotions.

The term "emotional intelligence" was recently used by Goleman [16], [17] while the scientific term was coined by Thorndike's social intelligence [18]. "Emotional Intelligence" is considered a multidimensional concept, so there are several definitions, depending on its aspect, that scientists are trying to cover, although most believe that emotional intelligence is composed of four characteristics: perception, understanding, control and use. of emotion and is defined as "a complex concept that includes a range of dimensions (abilities, characteristics, skills) and refers to various areas of human nature (cognitive potential, personality, behavior)" [19].
[6] states that according to the Greek Dictionary: Emotional Intelligence is defined as "the ability to control one's emotions, to deal with emotional stress, to develop one's abilities in areas such as imagination, art and human communication", while according to Goleman [19] it is defined as "the ability to know what you are feeling and to be able to handle these emotions before letting them handle you, to be able to motivate yourself to achieve your goals, to be creative, make the most of your skills, understand how other people feel and can handle their relationships effectively." Finally, researchers [20] define emotional intelligence as "the ability of an individual to recognize, accurately evaluate, and distinguish his or her own, others' emotions, to understand them, to assimilate them in their minds and to regulate both negative and positive emotions in themselves and in others."

According to researchers, there is a positive correlation between emotional intelligence and cognitive processes of the individual, emphasizing both the importance of emotional intelligence in emotion and knowledge, thus strengthening individuals and their personalities [21], [22] and point of view. that emotional intelligence is a skill that can be "learned" and developed. [23], [24].

Researchers Dringas & Papoutsi [25] in their research emphasize that the development of emotional intelligence is "based" on a 9-level model according to the concepts of Gardner's interpersonal and interpersonal meanings [26], [27].

The pyramid of emotional intelligence (9 level model).
1. Emotional Unity
2. Exceeding
3. Homogeneity of Emotions, Realization
4. Social Skills, Specialization in Emotions
5. Social Awareness, Empathy, Emotion Discernment
6. Self-management
7. Self-knowledge
8. Recognition of emotions, perception-expression of emotions
9. Emotional stimuli

As highlighted in the research and according to the following models [28], [29], [30], ICT helps to regulate and rise to higher levels of better functioning of mental emotional functions as man strives to reach the last level of the pyramid and at each level cultivates important emotional, cognitive and metacognitive skills that are important resources.

4. Autistic people's family and Emotional Intelligence

The search for a valid diagnosis and advice on the child's condition and 'what can be done about it' becomes a painful and traumatic experience for one or both parents, as they challenge the initial diagnosis or have the hope of a "miracle". regarding the treatment and cure of their child, while the lack of services or the lack of information of the specialists in the problems of developmental disorders but also the support they need creates negative emotions: insecurity, frustration, fatigue, questioning of the specialists but also loneliness regarding treatment and help "We swim in the ocean with a storm without a life buoy" describes the condition of a mother of an autistic person.

The initial shock of parents with the diagnosis of the disorder and the emotions that follow are common to all parents [31] regardless of national origin, socioeconomic status, education, area of residence and other factors [32] and it was observed that The emotions that burden the parents are chronic, physically and mentally and create them chronic physical fatigue "caseness" but also physical illnesses. [33], [34],[35]. In the beginning they are in order: shock, fear, feeling of isolation and uncertainty [36], followed by confusion and distrust for experts
and finally emotional disorganization [37] and then turn into depression, mood swings, low self-esteem, family disharmony and social dissatisfaction [38],[39].

Parents of autistic people go through a long path of emotional upset and disorganization [40] and go through a series of successive stages of adjustment [41] which are the most important:

a) Shock and Sadness: parents feel they are losing the child they had [42], the child they had dreamed of, a healthy child for whom they had made plans for the future and are suddenly told that it is autistic.

The diagnosis in the family, apart from the shock, also causes sadness, causes mourning because the parents were not prepared to accept this child, which is not what they expected and so they react in their own way: one parent will cry mourning, another is dedicated to work and leaves the problems behind to run, close the communication channels between them, "loads the burden" exclusively on the other, etc.

The period of mourning-sadness according to [43] and his collaborators can occur in three forms of reaction:

a) the parents to gradually experience the sadness and finally to completely overcome the grief.

b) some parents experience grief and frustration for years and

c) the third group of parents who experience grief with emotional regression. [43].

b) Denial: the emotion that follows shock and sadness is denial. Most parents refuse to accept what is happening and try to convince themselves that nothing is happening and that their child is normal and try to find excuses such as: "It can not happen under any circumstances!! It must be a mistake!!", "It's nothing, and his father was a closed guy, and as my mother-law says he was late to speak ".

c) Anger, rage, fear, low self-esteem, frustration: and after the denial and when they understand that the problem exists, a struggle begins with visits to specialists and they experience: anger, rage, indignation, panic, despair manifested by questions: "Why did this evil happen to us", "Why do you punish us, my God", "What is wrong with the child being oppressed", "What will we say to our friends? "No one will want us to live alone."

The anger and rage of the parents often turns into depression and despair and can be directed both against the experts and against God, whom they consider their punishment.

d) Guilt: most parents feel guilty and blame themselves or ask themselves, "Is it my fault?", "Is it something I did or did not do?" or to each other with expressions such as: "You smoked during pregnancy", "you were terribly anxious", "you drank a lot before conception", "you were aggressive during pregnancy", or "that uncle of yours had psychological problems".

The guilt feelings experienced by parents, as argued by [44], [45] are related to the reflexive reactions of disgust in disability and therefore it is difficult for parents to accept their child's disability, to live together with him [40] and fatally lead to exclusion from their relatives, relatives and friends and from their social environment with high percentages of stress. [46].

e) Acceptance - Concern: parents finally, when the diagnosis is finalized, are more concerned: about the severity of the disorder, about the future of the child, about the appropriateness of the treatment, about the ability of the specialists, about finding a suitable educational framework, about whether they will have appropriate and adequate counseling support and training. However, after the diagnosis, the parents may feel relieved because they are able to understand and give answers about their child's behaviors.

[47] report that the stages of parental reactions to the process of diagnosing autism and their adaptation are 6: a) manifestation of symptoms of the disorder, b) confusion of parents,
c) misdiagnosis, d) support, e) diagnosis of autism, f) acceptance / adaptation [32]

Other researchers such as [48] describe the stages of reaction and adaptation to the following 4: a) the stage of shock with strong emotions such as pain, anger, disbelief, confusion about the diagnosis, b) the stage of reaction with negative emotions that it can take years if the child does not receive the appropriate support; each stage.

Researchers claim that the traumatic and painful effects experienced by the family but with the diagnosis of autism are influenced by 3 categories of factors that interact: a) factors related to the disorder, b) intra-family factors and c) socio-environmental factors.[32], while others categorize the factors that affect the physical and mental health of parents and their quality of life into 4 categories concerning (a) the child with autism, (b) parents, (c) family and (d) the natural and social environment [49].

Below is a presentation of the first 2 ways of categorization.

a) Effects of the disorder on the family.

The effects of autism on the family are much more serious than other disorders such as mental retardation.[35]. Parents of autistic people have higher levels of anxiety, feel strongly indebted, fear and stress prevail [50], feel lonely and isolated [32] due to the difference in raising a child with autism that separates them from people around them, raised by typically developing children [51],[52]. Parents experience negative emotions (shame, guilt, frustration) when their child is at school age (age 6-7) because then his inclusion in the special and not in school for students of formal development and creates feelings of frustration. The same thing happens at the beginning of adolescence [52], [53], [54], [55]. But parents of children with autism also experience the diagnosis of autism differently. Fathers are possessed by strong emotions that are difficult to express, with the result that they run the risk of presenting physical and psychological problems, they worry about for the development of their child for his autonomy and have the concealment of feelings of pain through the expression of anger [56].

In a study by the Health Control Center, mothers of autistic students had higher levels of stress, depression than mothers of children with mental retardation [57], as well as in a study comparing stressful situations of mothers with autistic children and mothers with children with normal development. It was emphasized that the stress of mothers of children with autism and mothers of children with normal development was primarily associated with mothers with children with autism and mothers of children with autism were more prone to stress experiences [58],[59]. Other researchers have shown that low-functioning autistic children, hyperactive, low-adaptability and low-mood, are as stressful to mothers as those children, who have not developed speech skills [60].

However, despite the negative emotions that the diagnosis of autism causes in parents, they themselves point out that the diagnosis also has a positive effect. They emphasize as the first important emotion the strengthening of relations between the members of the family. This is what scientists-researchers point out because the parents of the child with autism develop the ability to "employ" stress management mechanisms for their better mental health [61], [62],[63].

Researchers have also pointed out that parents solve problems easily by managing members' crises and this is associated with a better quality of family life and the well-being of the mother regardless of the severity of autism [64]) resulting in the creation of a positive atmosphere in the family and the reduction of negative emotions [65],[40].

Finally, it should be emphasized that some parents of autistic children manage to "get out" of the quagmire of psycho-stressful situations by employing mechanisms that lead them to
overcome the daily difficulties that arise and enjoy their child's progress, they experience positive emotions. They stop staying in the diagnosis and observe the signs of their child's progress, they are happy and satisfied but they do not feel injustice of the child's presence in the family [66]. Also, parents experience positive emotions and optimism from the social support of friends, relatives.

b) Effects of autistic disorder on the family (intra-family factors)

The intra-familial factors that influence the reaction of the family and the adaptation of the new state of the diagnosis are classified into 2 categories [32]: a) in the category in which the factors relate to the parents' information about the disorder [67] and these are given by a team of experts, who guide, help the parents and inform them correctly and validly and b) in the category that the factors concern the psychological factors and the way the family works such as acceptance of diversity, stress management and way of solving problems. Stress management in families of children with autism helps the family to better adapt and is characterized by mental resilience. Lack of resilience leads mothers to intolerance and difficulty adjusting [68].

The following is a summary of the findings of intra-familial factors that affect family adjustment: [32]

- The intensity and frequency of conflicts between family members [69],[70]
- The paternal abandonment of the family [71],[72],[70]
- How to manage stress [44]
- Psychological characteristics of the family and its mode of operation [73],[74]
- The development of the child and his future [75]
- The degree of guilt of the mother [47]
- Ways to solve problems [67]
- The ability of the family to adapt to difficult conditions [35]

c) Environmental factors that affect the family

The degree of emotional burden of parents with the diagnosis of autism in the child depends on factors [40] such as: the time-consuming process of correct diagnostic evaluation. Prolonged assessment creates uncertainty and anxiety and is imperative to be correct as misdiagnosis can cause parents: confusion, despair, accusations, guilt, and social isolation [47].

Another factor that creates increased stress in the families of children with autism spectrum disorder is attributed to the lack of appropriate services according to the views of parents and researchers, and this creates stress and insecurity for parents if there is a lack of valid information from experienced and fully informed professionals. but also the quality of communication between specialists and parents [40]. According to the parents, the specialists who will evaluate their child and diagnose the disorder should provide them with a clear and complete knowledge about autism, show sensitivity in the way of "announcing" the result of the diagnosis, and guide them responsibly as to the way their children are treated.

The increased stress of families of children on the autism spectrum is attributed to the way in which the family copes with the stressful situations it experiences but also to the interaction of factors related to the characteristics of the family in terms of coping with stress and the quality of services provided.[57] resulting in affecting the way the family adapts.

The lack of state and social support, ie organized and appropriate diagnostic services for diagnosis and proper information create stress in parents,[67],[36].

Then the lack of appropriate treatment programs such that the child can meet the social demands of the environment seems to have an impact on parents as the literature indicates that there is a lack of acceptance of autism by society [35].
Parents argue that the assistance they receive from state and social support services is insufficient [76]. Greek parents also claim the same.

Finally, a factor that affects the family is the acceptance of autism by the family environment [35]. The positive attitude of their relatives (grandparents, siblings) helps parents because they (their relatives) understand autism [77]. In the Greek data, the majority of parents state that they have the support of their relatives.

Below is a brief presentation of the factors that determine the effect of childhood autism on parents according to [49].

According to the researchers, the factors that affect the functioning of the autistic person's family are divided into 4 categories.

- **Factors that burden parents negatively:**
  - The first category is related to the child who has been diagnosed with autism. Factors that burden parents negatively relate to the severity of the disorder and its symptoms [78],[79],[80] the child's character, personality his behavior, that is, his obsessions for a specific ritual way of performing the acts, the communication difficulties for social conciliation [81], [60], [82], [47], its level of functionality, eg low functionality of the child, self-injuries lead to exhaustion of parents as it is difficult to manage and deal with situations [79],[83],[84], the coexistence of other concomitant disabilities, eg mental retardation [85], [80], the degree of adaptation of parents to the problem, and the need to [86].
  - The factors that affect the functioning of the family and are negatively related to the parents are: the age of the parents when they are elderly parents plays an aggravating role [84], the financial situation because there are additional costs for care and the progress of the child eg speech therapy, occupational therapy, etc. or even limiting his work for child care [87], [83] the quality of the marital relationship, as well as research [88] have argued that parents who feel satisfied with their marital relationship show low levels of anxiety and depression, few problems in "raising" their child regardless of their financial level, social support and the child's difficulties, the personality of each parent, whether he / she has been overwhelmed by stress and how irritable he / she is [84], lack of knowledge - information n for the disorder [89] the time period from the suspicion of autism to the definitive diagnosis [47], [90].
  - On the contrary, the family is positively affected by the flexibility in the parental roles for the care of the child, so that if the exhaustion of one [91] avoids the system of values and beliefs, the philosophy-attitude for an optimistic approach to life [92] the concept of controlling the problem and its consequences, such as understanding, affection and support between parents [93], [94], form and ability to interpret the problem the way they interpret the disorder according to the philosophy and beliefs of the parents eg religious [95], [96], or passive meanings eg blame guilt that help parents cope better because they suppress personal guilt [90], older parents choose strategies, [90], [97], while the failure of parents to perform meaning in the disorder causes psychological problems and deterioration of quality of life [96], [91], the type of coping strategies, ie the implementation of appropriate effective ways to resolve practical and emotional situations eg stress management [67], [98], the degree of adaptation to it.

- **In addition to the factors concerning the parents, there are also factors that the factors that affect the functioning of the family, some positively and others negatively.**

  Positively affect the family: family ties, ie how strong the bond between the two parents is and this helps in their emotional discharge [35], the way of resolving tension problems, when tensions are resolved calmly [99], the way of communication between members, when there is
effective communication and equal participation of all members in decision making [81], the
degree of flexibility of the structure and function of the family, related to meeting the needs of
all members based on the stage of its development [67], [98], the family's ability to regenerate,
\( \text{ie the family's ability to function in a short period of time as before the onset of the disorder} \\
\text{[96], the application of collective (family) methods of dealing with the problem [67], [100].} \\
\)

Factors that negatively affect the family are: the existence of other stressors, eg
financial problems, illness of another member [89], the degree of permeability of its
boundaries, ie when there is a disturbance of boundaries in the balance of family boundaries
which either favors the increase of anxiety and stress and does not allow it to properly handle
anything related to the disorder: information or help services or to consume its energy without
result and lose its coherence [91].

\( e) \) Finally, the factors that influence and participate in the formation of the climate in
the family and come from the natural and social environment are the following:

Positive factors are considered: the extent and degree of mobilization of social
support services, ie services: health, welfare, education that provide adequate service, support
and assistance to parents and children[81] , [101], the type and the degree of adequacy of the
above services, the specialized programs for parents [ 90], the level of communication and
cooperation with the various professionals and services, their degree of sensitivity to the
problem, perceptions and attitudes towards the autism and the acceptance or not of the child,
the support of experts, friends, any groups that encourages and understands them [35], [82].

When parents feel that their social environment rejects and isolates them [92], [47], [98] then
they feel alone, weak and isolated. Stress and psychological problems in parents can also be
caused by experts with their attitude when they do not show the required sensitivity and respect
for the parents' problem and their needs [47], [83].

Finally, studies [49] concerning social and demographic characteristics show that the
family is burdened when:

1. resides in non-urban centers where there are no organized support and care
services [88], [102]
2. the mother is <30 years old, single or divorced, ie alone with low socioeconomic
Status [103] , [104]
3 .the child diagnosed with autism is a boy [105]
4 .the family had problems with dysfunction even before the onset of the disorder [105].

5. Investigations on the emotional charge of a family with a child with autism

Raising a child with autism spectrum disorder and exercising parental role has been
associated with high levels of stress, psychological distress, and there are a number of studies
examining the role of the problem's effects on parental mental health.

In recent years, surveys of families of children with autism compared to families of
children with other disabilities, as well as families of children with developmental disabilities,
have shown that parents of children with autism appear more upset, frustrated with their child's
needs, and his dependence on them in relation to the parents of the other groups of children
[106].

The following is a presentation of the research of the last decade where (a) research data
on the effect of childhood autism on mothers and fathers are presented, (b) the factors that
determine the degree and form of this effect are examined and (c) the interdisciplinary approach
required to address the various difficulties faced by parents and their families[49]. In a
qualitative study by [99], 57 parents of children with autism were found to have high levels of stress and depression, severe discomfort from the child's increased care needs, abandoning their personal goals and therefore there is also a limitation of their personal development.

[92] in a quantitative survey in 2001, with a sample of 58 parents of children with autism, found that parents have depression, social isolation and marital quarrels and disagreements.

Also, in a study by[107] report that parents of children on the autism spectrum have lower rates of employment and social participation than parents of children with normal development.

During 2002, three quantitative-comparative surveys were conducted:

1) parents of children with autism and parents of healthy children and the results showed: that in a sample of 66 parents of children with autism compared to the sample of the control group, 66 parents of healthy children, parents of autistic children showed more frequent family tensions and marital disorders. They showed more social isolation and received lower social support than the control group [67].

2) In two quantitative-comparative studies in 2002 of mothers of children with autism and control group of mothers of healthy children or children with other disabilities the results showed:

   a) in a sample of 29 mothers of children with autism and a sample of a control group 29 mothers of healthy children, in interviews, mothers of autistic people compared to mothers of healthy children stated that they put less emphasis on career, had less contact with the extended family, more emphasis and importance on discussions about children's problems than on any problems in their marital relationship. They also stated that they felt very uncertain about the child's future and the outcome of his condition but also that they had difficulty understanding the child's behaviors [95].

   b) with a sample of participants: 40 mothers of children with autism, 40 mothers of children with mental retardation, and 40 mothers of healthy children, mothers of autistic children, compared with control groups, showed higher levels of anxiety and depression, had more physical problems and experienced more severe psychosis; emotional exhaustion from raising their child [35].

Surveys in 2005 showed that:

   a) Qualitative ethnographic research of 28 parents of children with autism highlighted that religious belief helped parents solve their psychological problems more than the appropriate health professionals [97].

   b) Quantitative research of 53 parents of children with autism showed that parents showed normal levels of self-esteem, decreased happiness between them, increased divorce and inadequate approach and adjustment to the problem. Research has also shown that there was a positive effect of the problem: increased family bonding [94].

   c) and the quantitative research of 174 mothers of children with autism showed that mothers were possessed by high levels of anxiety, distress and stress [78].

   In 2006 surveys showed that:

   a) Quantitative and qualitative research by [89], 16 mothers of children with autism, showed that mothers have high levels of stress, depression and uncertainty about the child's future, and have existential concerns due to the unknown etiology of autism.

   b) the quantitative research of [108] with the participation of 15 parents of children with autism through an interview showed that parents feel sad but also angry for their lost dreams, have changed the priorities in their lives, the way of thinking about the role of the parent and the family role, have become aware of disability issues, the values of life have gained more
weight, the faith in God, the parents appreciate that the child with autism contributes positively both in the family and in society, their philosophy of life has changed and they appreciate and feel gratitude for what they have, optimism, hope.

c) [99] in a quantitative-comparative study, with the participation of 66 parents of children with autism and a control group of 66 parents of healthy children, parents with autistic children showed stress, greater psychological stress and emotional exhaustion than parents of healthy children, as well as greater aggravation physical health, but also isolation from relatives and friends. Finally, the research showed that in the family with an autistic child there was a weakening of cohesion between its members.

c) The researchers [60] in a quantitative research in Greece with a sample of 43 mothers of children with autism showed that mothers of autistic children show high levels of stress and anxiety from the care and upbringing of the child.

In a 2007 survey:

a) Regarding the process of parental acceptance of a child's disability, [109], in relation to the feeling of grief, with basic theoretical concepts: the stages of grief and chronic grief in their literature report state that during the stages of grief, parents, through a long-term process of "struggle" to accept their child's disability "reach" the acceptance of his disability, while parents are "paid" by chronic grief, the grief that prevails throughout the life of the child and appears strongly at critical moments of the child's development [110].

b) researchers [86] in quantitative-comparative, 459 parents of children with autism, 4,545 parents with other special learning and developmental needs and 11,475 parents of healthy children, parents of children with autism compared to control groups experience Most of the psychological and financial needs arising from the care and upbringing of the child leave the needs of their personal life due to the needs of the child, but the love, contact and connection with the child remain unchanged.

c) in a quantitative and qualitative [96] parents of children with autism showed that the diagnosis of autism positively changed the appreciation for the value of life and health, but also helped them to strive for the development of spiritual and personal progress through experience with autism.

d) [111] in a quantitative study of 364 parents of children with autism, showed that parents had high levels of stress, but also poor mental, physical and mental health. Also, the parents abandoned the needs of their personal life due to the care of the child, but were armed with patience and love for the child, discovered ways to solve problems in the family calmly, thus creating stability at home and family and also managed to exercise parental duties satisfactory. The parents also stated that they received adequate social support.

In 2008, [112] in a quantitative survey of 131 parents of children with autism presented the views of parents of children with autism who stated that the diagnosis of autism in the family showed a decrease in annual family income and there were many financial difficulties due to the child's needs.

Also, the results of [113] research report that parents of children with autistic disorders experience poorer quality of sleep than parents of children with normal development [114] conducted a study to investigate the relationship between quality of life and the feelings of mothers of children with autism. The study involved 104 mothers of children with autism and the results of the study showed that their quality of life was influenced by environmental factors, with a history of chronic disease, religion. Religion and the history of chronic disease negatively affected their lives.

A recent literature study by [115] in 25 articles lists the factors that affect the family of a person with autism but also the indicators that have a positive effect on its cohesion:
a) indicators of family resilience: self-efficacy, acceptance, sense of cohesion, optimism, positive family functioning.

b) risk factors such as: the severity of the symptoms, the family quality, the anger of the parents and the number of children with autism.

c) the protective factors that help caregivers to have a positive attitude towards the problem, such as: social support, the age of the child, the time from the diagnosis, place of control, cognitive evaluation and religious beliefs and spirituality.

[116] in a recent study (2010) present study examined the relationship between child behavior problem and parental mental health, acceptance, and empowerment. Participants included 228 parents of children diagnosed with autism and the results showed that psychological acceptance and empowerment were negatively affected by the severity of the parents' mental health problems associated with the child's problem behavior.

In 2012, [117] in a literature review of 22 studies on family resilience indicators show that parents of children with autism who have resilience indicators, ie self-efficacy [118], [119], [120], the acceptance [96], [121], [122], the sense of cohesion [123], [124], optimism [125], [126], [127], the positive functionality of the family [128], and enrichment [129] are better able to manage the rivalry associated with caring for children with autism.

Resilience and its indicators have been found to be associated with many positive health outcomes [130] and studies in parents with children on the autism spectrum, resilience indicators have been associated with positive parental mental health indicators, including low depression index [119], [125], [124], [132], better marriage quality [124], better psychological well-being [120], and greater life satisfaction [132].

In a study of 143 mothers of infants with autism, [119] found that increasing the effectiveness of parenting care predicted lower levels of depression. [132] found that lower severity of children's symptoms was associated with greater psychological well-being and life satisfaction and less depression. In addition, [131] found that satisfaction with social support was associated with low maternal distress in a sample of 97 American mothers of children with autism aged 2 to 18 years. At the same time, a study by [120] found that maternal self-efficacy, an indicator of resilience, was associated with less maternal depression and parenting anxiety. Also, [124] found a positive relationship between family quality and the ability to cope with stress.

A 2009 study by [133] looked at high-functioning autistic children (HFAs) and the impact on parental stress, sibling alignment and family functioning with results showing that parents of children with HFA have a high greater psychological anxiety than parents of children without a psychological disorder, which was found to be directly related to the characteristics of the children.

Researchers [123] conducted a study on the sense of cohesion and stress management between parents of children with autism and parents of typically developing children and then compared the level of cohesion and developing coping strategies anxiety. The research results showed that the parents of children with autism had a lower level of overall cohesion with no significant difference between the parents as the level of cohesion was positively associated with the search for social support and self-control and negatively with the acceptance of responsibility and positive feedback.

In a meta-analysis [134] on the impact of stress on parents comparing the way parents of children with and without autism spectrum disorder experience stress, researchers report that a significant difference between increased stress in children parents of children with ASD in relation to the stress experienced by parents of children without particular problems but also with parents of children with other disabilities: Down syndrome, cerebral palsy, etc.
n the Arab World - Jordan conducted by [135] a study on predicting the quality of life of parents of children with autism. A sample of 184 parents examined the variables: parental disorder, parent-child interaction, child characteristics, income, age, and number of siblings, and found that parental disorder alone was an important predictor of quality of life of both parents, while the characteristics of the child, the income of the households and the number of siblings only affect the quality of life of the mothers.

In a study by [136] on: the evolution of family interactions and parental stress with children on the autism spectrum. The sample of 176 married couples was asked to record on a daily basis 8 positive and 8 negative interactions between the spouses as well as his level of stress. The results indicate most days that parental stress and negative interactions prevailed and also highlight the need for parental support and help to find ways / methods to reduce the negative effects.

Also, another research study on stress among parents of children with and without autism was conducted by [137] (on 76 participating parents by completing questionnaires, taking saliva to measure cortisol and alpha-amylase and medical device for recording blood pressure for 24 hours. The results showed that the parents of children with ASD had quite high levels of discomfort, anxiety and depression compared to the parents of children without particular problems and referred to the need for support and help.

Another similar research study of parental stress and biological markers of cortisol, α-amylase, and blood pressure between two parents of a child with ASD [138] reported that mothers suffered from higher anxiety and depression than fathers, while fathers had higher blood pressure and heart rate variability.

[139] in a meta-analysis of 98 studies on the risks and defense factors for self-control of parental anxiety in children on the autism spectrum found that the risks faced by parents caring for their child with ASD are greater than those Defensive factors for the self-management of parents' stress, demonstrating the need for more training and specialization of health care providers (medical, nursing staff, etc.) in order to provide greater support for self-management of stress and the most essential care of children with ASD.

Also, a 2017 study by [140] In Northeast India on the effects of stress, coping, social support, and resilience of families with children on the autism spectrum showed that parents of children with autism exhibit specific stress, have limited personal time that adversely affected their professional life. but despite the plethora of stressors, family members had developed important rules and ways of dealing with them so that there could be harmonious coexistence. It would be worth mentioning that religion is often a haven as special help centers are scarce.

6. Conclusions
It is considered a given according to the research documentation that the parents of people with autism are physically and mentally exhausted daily and can lead to exhaustion with consequent consequences in all areas of their lives and social care is necessary for their help and support. in the struggle for the care of their children through programs and infrastructure

Most common effects reported by [141] irritability, social isolation, chronic fatigue and pain, loss of interest in favorite activities, frequent illnesses, difficulty concentrating, sleep habit changes, changes in appetite and weight, feeling of hopelessness or weakness, depression, anger, inappropriate use of drugs and alcohol, etc.

Irritability, social withdrawal, chronic fatigue, loss of interest in favorite activities, frequent illnesses and chronic pain, difficulty concentrating, changes in sleep patterns, changes in appetite and weight, feelings of hopelessness or weakness, anxiety, depression, use, depression [141].
From the above it follows that in the family of people with autism in addition to the personality, temperament and mental health of family members, important factors for its functioning are considered and a) The relationships of members, their way of communication, its dynamics b) the values, attitudes, beliefs, stereotypes of the family and its members in relation to autism disorder, c) the strategies used to solve and deal with the situations and problems that arise d) the social and financial support of the family from services or other bodies and finally e) the degree of use of social support services and the claim of rights [41].

References
Books.

[35] Weiss, M.J. Hardiness and social support as predictors of stress in mothers of typical
[60] Konstantareas MM, Papageorgiou V. Effects of temperament, symptoms severity and level of functioning on maternal stress in Greek children and youth with ASD. Autism 2006, 10:593–560


