

# The Relationship between Autism Spectrum Disorder among Children and Perceived Functioning among Parents in Italy

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**Abstract:** *Aim:* To evaluate how the life of a parent changes from a psychological, social and economic point of view and to investigate levels of anxiety and depression perceived from the moment of diagnosis of the child's Autism Spectrum Disorder (ASD).

*Methods:* From March to December 2021 an observational, cross sectional multicentre study was conducted.

*Results:* A total of 372 parents were recruited in this survey. From data collected, most of parents reported high depression than anxiety levels. Parents interviewed declared that in most of the life spheres, such as: social, working, family, the presence of their sons with ADS have importantly influenced their lives. No significant associations were recorded between the autistic child habits or behaviors and the presence of anxiety among participants. On the other hand, motor and vocalist which could create serious disturbance among neighborhood was significantly associated with depression condition ( $p=0.021$ ).

*Conclusions:* It has been shown that social, psychological and economic support from institutions and professionals is still very low.

**Keywords:** Anxiety, Autism Spectrum Disorders, Depression, Inclusion, Parents, Support.

## 1. INTRODUCTION

Autism Spectrum Disorder (ASD) is currently considered as a complex neuropsychiatric disorder with onset in developmental age, which presents a different variable clinical expression for each person and is configured as a permanent disability, with characteristics of social deficit that assume a variable expressivity in the time [1]. Developmental profiles of two children with ASD may be different at a macro level, but have difficulties in common such as: problems in communicating, relationship difficulties and

repetitive behaviors [2] that occur in extra-family environments, such as school of childhood or primary school. Parenting a child with autism spectrum disorders can lead to stressors related to the child's difficulty in communicating, dysfunctional behaviors, social isolation, self-care difficulties, and a lack of understanding. As can be seen from several studies in the literature, children with Autism Spectrum Disorder are more vulnerable to sleep disorders: an Indian study by [3] conducted on 73 children between 3 and 12 years of age with typical and 73 children between 3 and 12 years with ASD show more sleep problems in the latter than in able-bodied children. A review of the studies highlights an emerging problem: food selectivity which is estimated to be around 60/70% of children with ASD, with a diet restricted to very few foods and

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the aversion to specific flavors, colors, textures and temperatures [4]. It is pleonastic to underline how individual, parental, marital, social and financial stress overwhelms the lives of parents, who feel desperate, exhausted and powerless in the face of this new situation. This parental stress has repercussions on the balance of the entire family unit, on relations with the partner, with less marital satisfaction, on social relations [5]. The quantity and quality of time that everyone dedicated to himself before being diagnosed totally changes, with serious repercussions both in private life and in the working world. The birth of a disabled child, the onset of the first signs and symptoms of the disorder, the consequences of the diagnosis plunge the whole family into despair, leading them to isolate themselves from society. The diagnosis of autism spectrum disorder can greatly affect the relationship between parent and child. It is precisely from the first years of life, and thanks to the relationship established with the parent, that the child acquires certain skills. Furthermore, from this reciprocal and intersubjective exchange, the mental structures predisposed to relationships, interactive exchanges and mutual communication are formed, basic skills in language acquisition, alternation of turns and the intentionality of the child [6]. At this stage, with the onset of acceptance problems, the awareness of disability, the reorganization of the entire parental life, families with a disabled child tend to differentiate themselves from the others [7]. Each parent experiences the moment of diagnosis differently; while in some cases this diagnosis is considered as the confirmation of one's doubts and concerns with consequent acceptance, in others the reactions lead to shock, pain, disbelief and denial. You realize you are alone and helpless in the face of a lifelong problem and, worst of all, you are faced with the misunderstandings of relatives and friends. In this scenario, feelings such as shame, anger, humiliation, fear of being "judged" prevail. Mothers experience a sort of "wounded motherhood", they are more prone to be ashamed of their child's problems and, as a result, their identity is also threatened as a mother's perception of her own caring for her child significantly affects how in which the meaning of one's life is defined [8]. It seems that fathers mostly indirectly experience the effects of autism in their children, as they believe that the most serious impact for them is how their wives experience the disorder, since the latter also has repercussions in the couple relationship [9]. Many and almost always insurmountable are the

difficulties that parents have to face: lack of interaction with their child, social misunderstanding, behavioral disturbances, uncertainty about the future and the impossibility of leading a normal life. The aim of the study is to detect how a parent's life changes and the levels of anxiety and depression perceived by their child's ASD diagnosis.

## 2. MATERIALS AND METHODS

### 2.1. Study Design

Cross-sectional, multi-center observational study.

### 2.2. Study Procedure

The study was carried out through the electronic disclosure of an online survey tool, as it was considered an effective, safe (for the current Covid-19 pandemic and containment measures) and inexpensive method to find a large number of participants among the parents of children with Autism Spectrum Disorder. The study was conducted nationwide, through a Snowball Sampling sampling. Each parent could join it, completely anonymously, through a link. They were contacted through:

- Facebook groups at regional and national level: Autism is; Autism is Puglia; Autism is Calabria; Autism is Sardinia; Autism is Emilia-Romagna; Autism is Sicily, Autism is Campania; Autism is Lazio; Autism 2-18 years; The world of Derek "The big three" -Autism "; Autism is not contagious: the group; Speech Disorder, Autism Spectrum, Selective Mutism or Related; Autism, knowing means understanding; Autism / Asperger's in children and adolescents; AUTISM not a world apart but part of the world; Autism: whoever stops is lost; Autism (Italy);
- Instagram Pages: Autism on the move; Autism Blue Hearts; A family in blue;
- ANGSA Association (National Association of Autistic Parents) at regional and national level thanks to the contribution of Luciana Zecca, Provincial President (Lecce) of the Association.

### 2.3. The Questionnaire

The questionnaire used for data collection consists of 5 sections:

1. The first section is aimed at collecting the socio-

demographic data of the parent (geographic area in which he lives, gender, age, marital status, with whom he lives, level of education and religious belief);

2. The second section (12 items) aimed at collecting information on knowledge about the Autism Spectrum Disorder, the first diagnosis and the age of the child at the time of the same;

3. The third section (17 items) aims to evaluate how and through which sources the parents received help and information regarding the diagnosis;

4. The fourth section (21 items) in which it is assessed how the participant in the study would define his state of health at the time of completing the questionnaire, the state of mind at the time of diagnosis, how the latter influenced daily life, by which figures you are supported, which are the most difficult moments during the day and what type of support would you need;

5. In the last section the parent is asked how he usually feels through the scale (Forma -Y-1- and Y-2) [10,11], a test of 20 items, each with 4 degrees of response and how they felt in the last two weeks (including the day of filling in the questionnaire) through the BDI-II (Back Depression Inventory) scale, a test of 21 items [12].

All sections of the questionnaire were computerized through the use of a pre-set form from the Google Drive platform. The study ran from March 2021 to December 2021. Inclusion and exclusion criteria

All parents of children with Autism Spectrum Disorder, belonging to the Italian population, who agreed to participate in the study by signing the informed consent were included. Excluded all those who did not have a component (a child) with Autism Spectrum Disorders and / or those who did not agree to join the study.

#### **2.4. Data Analysis**

All data were collected in an Excel data sheet and processed thanks to the SPSS, IBM, version 20.

Data were showed as categorical variables and were presented as frequencies and percentages.

Then, linear regressions were performed in order to assess which factors assessed among parents influenced their anxiety and depressions conditions.

Statistically significant values were assessed for all p-values <0.05.

#### **2.5. Ethical Considerations**

Ethical characteristics of the study were stated within the presentation of the questionnaire. It was pointed out that participation was voluntary and that the participant could refuse participation in the protocol at any time. Interviewers enrolled preliminarily gave their informed consent forms, which reminded to their voluntary nature of participation, as well as the confidentiality and anonymous nature of the information, too. In addition, to ensure that the questionnaires were anonymous and to allow the identification of the participants, a sequential identification number (ID) was assigned to each registered participant. Therefore, each questionnaire was identified by an ID number corresponding to the ID of the SPSS database.

#### **3. RESULTS**

A total of 372 parents were recruited in this study. All participants had one son with ADS. Table 1 showed all sampling characteristics collected.

#### **4. DISCUSSION**

The study aimed to evaluate how a parent's life changes from a psychological, economic and social point of view and investigate the levels of anxiety and depression perceived from the moment of diagnosis. The sample that joined the project is made up of 372 parents of people affected by Autism Spectrum Disorder, of which 43% (n=160) resident in the regions of the South-Islands, 41.4% (n. = 154) in the Northern regions and 15.6% (n=58) in Central Italy. The results of the study show a prevalence of the female gender (n=341) with a percentage of 91.7%. The average age of the parents who participated in the study was 40.1 years. 70.7% (n. = 263) of the sample is married, 16.1% (n=60) cohabiting, 7.8% (n=29) divorced, 4% (n=15) single / single and 1.3% (n=5) widower. As many as 42.2% (n=157) of the 372 participating parents believe that current knowledge about ASD is scarce. Although the knowledge (since its discovery in 1943 with Leo Kanner) is constantly developing thanks to the work of numerous research groups throughout the world and thanks to the greater training of doctors and health professionals specializing in the sector, there are still many uncertainties about the etiology, clinical picture, diagnosis and management of the

**Table 1: Sampling Characteristics (n=372)**

Sampling Characteristics	n(%)
<b>Sex</b>	
Female	341(91.7)
Male	31(8.3)
<b>Age</b>	
Until 30 years	23(6.2)
31-40 years	164(44.1)
41-50 years	165(44.4)
51-60 years	19(5.1)
Over 61 years	1(0.3)
<b>Part of Italy belonging</b>	
North (Liguria, Lombardia, Piemonte, Valle d'Aosta, Emilia-Romagna, Friuli Venezia-Giulia, Trentino-Alto Adige, Veneto)	154(41.4)
Center (Lazio, Marche, Toscana, Umbria, Abruzzo)	58(15.6)
Southern-Islands (Basilicata, Calabria, Campania, Molise, Puglia, Sardegna, Sicilia)	160(43)
<b>Marital status</b>	
Unmarried celibate	15(4)
Conjugated / conjugated	263(70.7)
Divorced / divorced	29(7.8)
Widow / widower	5(1.3)
Cohabitant	60(16.1)
<b>Educational level v</b>	
None	0(0)
Primary school diploma	6(1.6)
Higher middle school license	211(56.7)
Diploma	146(39.2)
Degree	9(2.4)
PhD	0(0)
<b>Who do you live with?</b>	
Alone	13(3.5)
With partner and/or sons	312(83.9)
With parents / family	47(12.6)
<b>Religious believing</b>	
Christianity	308(82.8)
Islam	0(0)
Buddhism	2(0.5)
Hinduism	0(0)
Judaism	0(0)
Atheist	62(16.7)
<b>Current knowledge on ADS:</b>	
Nothing	4(1)
Scarce	157(42.2)
Sufficient	96(25.8)
Good	81(21.8)
Excellent	34(9.1)
<b>From which institutions did you receive help at the time of the diagnosis?</b>	
Healthcare systems	254(68.3)
Other (School, Family, Church, No institution)	118(31.7)

Did you receive a "clear picture" of your child's characteristics associated with ADS at the time of diagnosis?	
Yes	110(29.6)
No	262(70.4)

From data collected, most of parents reported high depression than anxiety levels (Table 2).

**Table 2: Anxiety and Depression Levels among Parents with an Autistic Son**

	Absence n(%)	Mild n(%)	Moderate n(%)	Severe n(%)
Anxiety (S.T.A.Y.-2)	76(20.4)	228(61.3)	63(16.9)	5(1.3)
Depression (DBI-II)	69(18.5)	122(32.8)	109(29.3)	72(19.4)

Parents interviewed declared that in most of the life spheres, such as: social, working, family, the presence of their sons with ADS have importantly influenced their lives (Table 3).

**Table 3: How the Diagnosis of ASD (Autism Spectrum Disorders) Influenced Social, Working and Family Life among Parents**

Items/level perceived	In no way	Little	Enough	Very
Relationships with friends / relatives	38(10.2)	89(23.9)	119(32)	126(33.9)
Relationships with work colleagues	98(26.3)	124(33.3)	86(23.1)	64(17.2)
Relationships with other family members	60(16.1)	111(29.8)	113(30.4)	88(23.7)
Relationships with the partner	56(15.1)	83(22.3)	132(35.5)	101(27.2)
The time I devoted to myself	8(2.2)	38(10.2)	83(22.3)	243(65.3)
The time I devoted to other family members	21(5.6)	72(19.4)	126(33.9)	153(41.1)
My commitment in the professional field	43(11.6)	54(14.5)	109(29.3)	166(44.6)

Table 4 showed the most difficulties reported by parents during their daily lives.

**Table 4: The Most Difficult Daily Moments among Parents with an Autistic Son**

Items/level perceived	Never	Rarely	Often	Always
In the morning as soon as you get up	67(18)	217(58.3)	66(17.7)	22(5.9)
During meals	63(16.9)	178(47.8)	95(25.5)	36(9.7)
In the evening before falling asleep	54(14.5)	203(54.6)	90(24.2)	25(6.7)

No significant associations were recorded between the autistic child habits or behaviors and the presence of anxiety among participants (Table 5).

**Table 5: How the Autistic Child Habits or Behaviors Influenced the Presence of Anxiety among their Parents?**

Items	Non-standardized coefficients		Standardized coefficients	t	p-value	Confidence interval 95%	
	B	Standard deviation Error	B			Min.	Max.
Poor cognitive abilities	.021	.043	.029	.493	.622	-.063	.105
Difficulty in relating with his teammates	-.001	.043	-.002	-.033	.973	-.086	.083
Motor and vocal tics on a daily basis that create serious disturbance	-.017	.041	-.025	-4.19	.676	-.097	.063
Threatens or physically attacks people, even animals, damaging objects	-.074	.062	-.096	-1.199	.231	-.195	.047
Mind to gain advantage	.047	.052	.053	.900	.369	-.055	.148
Appropriating objects that do not belong to him	.017	.045	.024	.368	.713	-.073	.106
Try to get what he wants by force	-.048	.053	-.073	-.912	.362	-.151	.055
Presents sudden outbursts of anger towards adults	-.011	.048	-.017	-.222	.825	-.105	.084
Ignoring what he is told or does the opposite	.052	.047	.076	1.097	.274	-.041	.145
Quarrelsome and angry character	-.016	.057	-.023	-.275	.783	-.129	.097
Deliberately irritates friends, companions, and relatives	.074	.065	.093	1.138	.256	-.054	.201
Being sensitive, spiteful and vengeful towards others	.036	.058	.050	.631	.529	-.077	.150

\*p<0.05 is statistically significant.

On the other hand, motor and vocalist which could create serious disturbance among neighborhood was significantly associated with depression condition (p=0.021), (Table 6).

**Table 6: How the Autistic Child Habits or Behaviors Influenced the Presence of Depression among their Parents?**

Items	Non-standardized coefficients		Standardized coefficients	t	p-value	Confidence interval 95%	
	B	Standard deviation Error	B			Min.	Max.
Poor cognitive abilities	.054	.064	.048	.850	.396	-.071	.180
Difficulty in relating with his teammates	-.009	.064	-.008	-.144	.886	-.135	.117
Motor and vocal tics on a daily basis that create serious disturbance	.141	.061	.135	2.326	.021*	.022	.261
Threatens or physically attacks people, even animals, damaging objects	-.011	.092	-.009	-.120	.904	-.192	.170
Mind to gain advantage	-.020	.077	-.015	-.256	.798	-.172	.132
appropriating objects that do not belong to him	-.013	.068	-.012	-.196	.845	-.147	.120
Try to get what he wants by force	-.033	.079	-.033	-.425	.671	-.188	.121
Presents sudden outbursts of anger towards adults	.065	.072	.067	.901	.368	-.077	.206
Ignoring what he is told or does the opposite	.139	.071	.132	1.955	.051	-.001	.278
Quarrelsome and angry character	-.016	.086	-.015	-.185	.853	-.185	.153
Deliberately irritates friends, companions, and relatives	.080	.097	.066	.829	.408	-.110	.270
Being sensitive, spiteful and vengeful towards others	.020	.086	.018	.232	.816	-.150	.190

\*p<0.05 is statistically significant.

Additionally, the sense of inadequacy to deal with the ADS child seemed to be significantly associate to the presence of anxiety conditions among parents (Table 7).

**Table 7: How the Daily Difficulties in Caring Autistic Child Influenced the Presence of Anxiety among their Parents?**

Items	Non-standardized coefficients		Standardized coefficients	t	p-value	Confidence interval 95%	
	B	Standard deviation Error	B			Min.	Max.
The own son's attitudes	-.033	.042	-.045	-.799	.425	-.115	.049
Judgments, criticisms from friends, relatives	-.026	.039	-.041	-.653	.514	-.103	.052
Fear of being considered inept parents	.027	.044	.045	.610	.542	-.060	.114
Sense of inadequacy	.163	.045	.259	3.629	>0.001*	.075	.252
Lack of assistance	.026	.052	.036	.503	.615	-.075	.127
Uncertainty about the future	.030	.070	.026	.431	.667	-.108	.169
Lack of support from institutions, families, health organizations	-.041	.055	-.053	-.744	.458	-.149	.067
Inadequate lifestyle	-.032	.046	-.046	-.699	.485	-.122	.058

\*p<0.05 is statistically significant.

Finally, the son's perceptions, sense of inadequacy an inadequate lifestyle appeared to be significantly associated with depression among participants (Table 8).

**Table 8: How the Daily Difficulties in Caring Autistic Child Influenced the Presence of Depression among their Parents?**

Items	Non-standardized coefficients		Standardized coefficients	t	p-value	Confidence interval 95%	
	B	Standard deviation Error	B			Min.	Max.
The own son's attitudes	.115	.057	.101	2.026	0.044*	.003	.226
Judgments, criticisms from friends, relatives	-.028	.053	-.029	-.519	.604	-.132	.077
Fear of being considered inept parents	.118	.060	.127	1.954	.052	-.001	.236
Sense of inadequacy	.227	.061	.234	3.708	>0.001*	.106	.347
Lack of assistance	-.022	.070	-.020	-.321	.749	-.160	.115
Uncertainty about the future	.118	.095	.065	1.238	.217	-.069	.305
Lack of support from institutions, families, health organizations	.145	.074	.123	1.946	.052	-.002	.291
Inadequate lifestyle	.160	.062	.151	2.574	.010*	.038	.283

\*p<0.05 is statistically significant.

person with ASD [13]. The diagnosis of Autism Spectrum Disorder puts an end to the "dream" of having a perfect and healthy child: anger, helplessness, depression and guilt take over. The moment of diagnosis is therefore a very delicate and decisive moment for the life of every parent and it is therefore essential to receive help and be supported at the time of the diagnosis. When it is not possible to overcome this initial pain, it could have repercussions

in the parent-child relationship: an attitude of rejection and estrangement or an overprotective attitude could characterize the parent after the diagnosis [7]. In our study, 70.4% (n = 261) of the sample said they did not receive a "clear picture" of their child's characteristics associated with Autism Spectrum Disorder at the time of diagnosis, a significant fact that draws attention on the uncertainties that still characterize the diagnosis and the clinical picture today: it is essential to underline

how Autism could present itself differently from person to person, with typical signs and behaviors for everyone [14]. 68.3% (n = 254) of the sample claimed to have received help from the Health Systems at the time of diagnosis, however, 31.7% (n = 118) received it from other institutions such as school, church, the family itself or, sometimes, unfortunately by no institution. A national survey in the UK of over 1000 parents found that 60% expressed dissatisfaction with post-diagnostic support and only 5% were very satisfied with it, and 46% said they did not receive a follow-up appointment. -up after diagnosis [15]. The diagnosis of ASD is like a bolt from the blue, from that moment the entire social, work and family life is affected; everything will revolve around the needs of the child. The results of our study highlight how the time that each parent devotes to himself (n =243; 65.3%), to other family members (n=153; 41.1%) and to professional commitment (n=166; 44.6%). Relationships with friends / relatives (n=119; 32%), with the partner (n=132; 35.5%) and with other family members (n=113; 30.4%) are quite influenced. All this could lead to different situations of stress and upset the balance of the entire family unit. Difficulties in couple intimacy appear to be frequent, with differences on the management of the child leading to a high incidence of divorces between the parents of children with ASD [16], as emerges in the literature. Studies in the literature also focus attention on brothers and sisters not affected by ASD: they show an increase in anxiety and depression, internalized and psychological behavioral problems [5]. The disorientation resulting from the diagnosis, in addition to leading to conflicts in the couple, could lead to an excessive commitment to the child with ASD at the expense of time and attention paid to other family members. The disability that affects a family member throws the whole family into pain and anguish, rendering them impotent and forcing them to change their habits and daily rhythms of life, seeking a new identity over time and requiring psychological support for this. A serious burden consists in the fear of not being adequate as parents and of not being able to respond to the new needs that this condition entails [17]. Additionally, the sense of inadequacy to deal with the ADS child seemed to be significantly associate to the presence of anxiety conditions among parents. The growth of the child with ASD is not directly proportional to the achievement of autonomy, but rather, with the passing of the years the difficulties related to the aging of parents who are no longer able to assist their child increase [7]. This is why ASD lasts a lifetime and

requires continuous assistance because it "upsets" the daily lives of those that provide care.

Therefore, post-diagnostic social support is essential not only for children with ASD, but also for their family in order to counteract depression, anxiety and perceived stress.

To understand the needs of families with ASD, a survey developed by Autism Speaks was established, promoted by the University of Cambridge, in collaboration with the National Coordinators for Autism of 9 Balkan countries. This survey found parents and families of children with ASD face significant financial difficulties and need better services in the health, educational and social sectors [18].

The Indian study, conducted on 73 children between 3 and 12 with typical development and 73 children between 3 and 12 with ASD, found more sleep problems in the latter than in able-bodied children. Parents of children with Autism Spectrum Disorder reported higher incidences of psychological distress, including depression and anxiety compared to parents of typically developing children, Down syndrome or other disabilities. The literature shows that mothers of autistic subjects are much more dissatisfied, frustrated and worried about their child's need for constant assistance than mothers of children with Down's Syndrome [7]. Among the 371 study participants it was found that 18.5% (n=69) did not have depression, 32.8% (n=11) mild depression, 29.3% (n 199) moderate depression and 19.4% (n=72) severe depression; perceptions of one's child's attitudes (such as daily motor and vocal tics that create serious neighborhood disturbances), sense of inadequacy and inadequate lifestyle are significantly associated with depressive conditions among the participants. Mothers of children with ASD experienced a greater care burden and depression than fathers (Scherer *et al.*, 2019). From the study by Kütük *et al.* [19] it appears, however, that both mothers and fathers of children with ASD had higher levels of burnout and depression than the mothers and fathers of the control group (without ASD). As a result, parents of children with ASD were more likely to have high BDI scores.

In this regard, psychological support from suitably trained professionals in the sector is essential. Families urgently need to have a network of specific, detailed and coherent services available from the first years of the child's life. Pediatricians of Free Choice and General Practitioners should have specific training in order to be able to recognize suspicious cases as soon



as possible and thus be able to refer families to specialists in the sector. In fact, our study revealed a significant association between a sense of inadequacy in dealing with the child with ADS and the presence of anxiety conditions among the parents. Parents should receive useful information on the diagnosis and problems of Autism as soon as possible in order to be able to deal with the child's problems immediately and in the best possible way. Unfortunately, all this today is "a utopia", the reality is quite different. In addition to health, a fundamental and essential role in aid to families, it is up to the school world. Despite the "decompensation" that the arrival of an autistic child could bring to the classroom, the school must be prepared to welcome and integrate: integration must be pursued in everyone's school [20]. Fundamental would be the figure of the school nurse and the family and community nurse, who could certainly facilitate student development and school inclusion, and alleviate the care burden of their parents. A key role is played by the occupational therapist as an intervention by her, in addition to improving the quality of life of the child, helps to reduce the pressure of care. In fact, following occupational therapy sessions, there is a decrease in behavioral symptoms and a greater involvement in the activities of daily life by the child. Furthermore, it is possible to carry out parent training to improve relational skills, for the management of food selectivity as demonstrated by some studies conducted during the lockdown period [21,22].

#### 4.1. Limitations

The results of the study must be considered taking into account some limitations that mainly concern the choice of electronic dissemination of the questionnaire that may have partially excluded parents that do not have computer access or have poor computer access. Possible information bias may be due to a reluctant attitude to declare and therefore admit a lack of knowledge of the phenomenon. Therefore, data cannot be generalized to other populations or geographic areas.

## 5. CONCLUSIONS

The aim of the study was to evaluate how a parent's life changes from a psychological, social and economic point of view and to investigate the levels of anxiety and depression perceived from the moment of diagnosis of Autism Spectrum Disorders. Lack of training, lack of support and services, misinformation and scarce support from adequate professional figures, as demonstrated by various studies in the literature and by the research project, lead the family to isolate

themselves. Uncertainty about the future, fear of being discriminated against and the lack of prospects can lead to parental stress in anxiety and depression. The results obtained from our study, have shown the still scarce knowledge about this disorder despite the continuous evolution. Furthermore, it has been shown that social, psychological and economic support from institutions and professionals is still very low.

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## CONFLICT OF INTEREST

The Author declare none commercial associations (e.g. consultancies, stock ownership, equity interest, patent/licensing arrangement etc.) that might pose a conflict of interest in connection with the submitted article.

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## AUTHOR CONTRIBUTIONS

Conceptualization: R.L. and F.T. and E.DA.; methodology: A.L. and E.V.; software: C.C. and S.Z. and R.L.; validation: E.V. and R.L.; formal analysis: E.V.; investigation: R.L. and A.B. and S.L. and A.C.; resources: E.DA. and L.V.; data curation: E.V. and F.C.; writing—original draft preparation: R.L. and E.V.; writing—review and editing: E.V. and R.L. All authors have read and agreed to the published version of the manuscript.

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## INFORMED CONSENT STATEMENT

Informed consent was obtained from all subjects involved in the study.

## DATA AVAILABILITY STATEMENT

Data are available at the latest Author for reasonable request (roberto.lupo@uniba.it)

## REFERENCES

- [1] Surian, L. Un dibattito sulla Linea Guida 21 «Il Trattamento dei disturbi dello spettro autistico nei bambini e negli adolescenti». *Psicologia clinica dello sviluppo* 2012; 16(3): 599-599.

- [2] Truzoli, R. *Aba per bambini con comportamento autistico. Principi teorici e strumenti applicativi* 2021, 1.
- [3] Tyagi, V.; Juneja, M.; Jain, R. Sleep problems and their correlates in children with Autism Spectrum Disorder: an Indian study. *JADD* 2019; 49(3). <https://doi.org/10.1007/s10803-018-3820-6>
- [4] Ferramosca, M.P.; Lupo, R.; Carriero, M.C.; Pilon, A.; Primativo, C.; Vitale, E. Can the parent training technique reduce parental stress in the food selectivity of children with autism spectrum? *Minerva Psychiatry* 2021; 62(4): 241-7. <https://doi.org/10.23736/S2724-6612.21.02184-9>
- [5] McConkey, R.; Cassin, M.T.; McNaughton, R. Promoting the Social Inclusion of Children with ASD: A Family-Centred Intervention. *Brain Sci.* 2020; 10(5): 318. <https://doi.org/10.3390/brainsci10050318>
- [6] Simonelli, A. *La funzione Genitoriale. Sviluppo e psicopatologia.* Milano: Raffaello Cortina, 2014.
- [7] Marrone, M. Il sistema famiglia in presenza di un figlio con autismo. *L'integrazione scolastica e sociale* 2015; 14(4): 389-407.
- [8] Shu, B.C.; Hsieh, H.C.; Hsieh, S.C.; Li, S.M. Toward an understanding of mothering: the care giving process of mothers with autistic children. *J Nurs Res.* 2001; 9(5): 203-13. <https://doi.org/10.1097/01.JNR.0000347577.24468.ae>
- [9] Gray, D.E. Gender and coping: the parents of children with high functioning autism. *Soc Sci Med.* 2003; 56(3): 631-42. [https://doi.org/10.1016/S0277-9536\(02\)00059-X](https://doi.org/10.1016/S0277-9536(02)00059-X)
- [10] Spielberger, C.D. *State-Trait Anxiety Inventory: Bibliography* (2nd ed.). Palo Alto, CA: Consulting Psychologists Press, 1989.
- [11] Spielberger, C.D.; Gorsuch, R.L.; Lushene, R.; Vagg, P.R.; Jacobs, G.A. *Manual for the State-Trait Anxiety Inventory.* Palo Alto, CA: Consulting Psychologists Press, 1983.
- [12] Beck, A.T.; Steer, R.A.; Ball, R.; Ranieri, W. Comparison of Beck Depression Inventories -IA and -II in psychiatric outpatients. *J Pers Assess.* 1996; 67(3): 588-97. [https://doi.org/10.1207/s15327752jpa6703\\_13](https://doi.org/10.1207/s15327752jpa6703_13)
- [13] Ministero della Salute. *Linee guida 21, Il trattamento dei disturbi dello spettro autistico nei bambini e negli adolescenti, Sistema Nazionale per le Linee Guida, 2015.* Data di pubblicazione: Ottobre 2011; data di aggiornamento: Ottobre 2015. Available from: <https://www.autismeurope.org/wp-content/uploads/2017/08/Il-trattamento-dei-disturbi-dello-spettro-autistico-nei-bambini-e-negli-adolescenti.pdf>. Accessed on October 1, 2022.
- [14] National Health Service. (2019). *Autism Spectrum.* Available from: <https://www.nhs.uk/conditions/autism/signs/children/> Accessed on September 20, 2022.
- [15] Crane, L.; Chester, J.W.; Goddard, L.; Henry, L.A.; Hill, E. Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism.* 2016; 20(2): 153-62. <https://doi.org/10.1177/1362361315573636>
- [16] Hartley, S.L.; Barker, E.T.; Seltzer, M.M.; Greenberg, J.S.; Floyd, F.J. Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *Am J Intellect Dev Disabil.* 2011; 116(1): 81-95. <https://doi.org/10.1352/1944-7558-116.1.81>
- [17] Annunziata, R. L'approccio sistemico relazionale e la presa in carico della famiglia del soggetto autistico. *Phenomena Journal - Giornale Internazionale Di Psicopatologia, Neuroscienze E Psicoterapia* 2021; 3(2): 93-100.
- [18] Zorcec, T.; Pop-Jordanova, N. Main Needs and Challenges of Parents of Children with Autism Spectrum Disorder. *Pril (Makedon Akad Nauk Umet Odd Med Nauki).* 2020; 41(2): 81-88. <https://doi.org/10.2478/prilozi-2020-0036>
- [19] Kütük, M.Ö.; Tufan, A.E.; Kılıçaslan, F.; Güler, G.; Çelik, F.; Altıntaş, E.; Gökçen, C.; Karadağ, M.; Yektaş, Ç.; Mutluer, T.; Kandemir, H.; Büber, A.; Topal, Z.; Acikbas, U.; Giray, A.; Kütük, Ö. High Depression Symptoms and Burnout Levels Among Parents of Children with Autism Spectrum Disorders: A Multi-Center, Cross-Sectional, Case-Control Study. *J Autism Dev Disord.* 2021; 51(11): 4086-4099. <https://doi.org/10.1007/s10803-021-04874-4>
- [20] Conte, L.; Lupo, R.; Mazzarella, C.; Calabrò, A.; Vaglio, L.; Chirizzi, S.; Donadio, C.; Carvello, M.; Marsella, A.; Artioli, G.; Vitale, E. Autism Spectrum Disorders and inclusion attitudes in the Italian school environments: teachers' knowledge, attitudes, perceptions and their necessity to consult a healthcare multidisciplinary team. *Acta Biomed.* 2022; 93(4): e2022284.
- [21] Grumi, S.; Provenzi, L.; Gardani, A.; Aramini, V.; Dargenio, E.; Naboni, C.; Vacchini, V.; Borgatti, R.; Engaging with Families through On-line Rehabilitation for Children during the Emergency (EnFORCE) Group. Rehabilitation services lockdown during the COVID-19 emergency: the mental health response of caregivers of children with neurodevelopmental disabilities. *Disabil Rehabil.* 2021; 43(1): 27-32. <https://doi.org/10.1080/09638288.2020.1842520>
- [22] Ganesan, B.; Fong, K.N.K.; Meena, S.K.; Prasad, P.; Tong, R.K.Y. Impact of COVID-19 pandemic lockdown on occupational therapy practice and use of telerehabilitation - A cross sectional study. *Eur Rev Med Pharmacol Sci.* 2021; 25(9): 3614-3622.

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