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# Psychological Adaptation in Parents of Children with Autism Spectrum Disorders

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## 1. Introduction

Autism and Autism Spectrum Disorders (ASD) are among the most enigmatic and restricting disorders, given that affected individuals demonstrate alterations in three basic areas of development: reciprocal social interaction, verbal and non-verbal communication, and flexibility in their selection of interests and behaviours. The peculiar characteristics that define ASD cause major disturbances in the family dynamics and generate needs in all areas and contexts of development (Altiere, 2006; Baker et al., 2005; Shu, 2009; Smith, Hong et al., 2010).

Other problems are frequently associated with the nuclear characteristics of autism. These include mental retardation (Sigman & Caps, 1997) and behaviour problems such as stereotyped, self-injurious or aggressive conduct (Bryson, 1996; Hastings, 2003) that persist in the long term (Einfeld, Tonge & Rees, 2001). These problems, depending on the severity and frequency with which they occur, will affect the development of individuals with autism and the well-being and adaptation of their parents to a greater or lesser extent (Herring, et al., 2006; Lecavalier et al., 2006; Pozo et al., 2006; Tomanik et al., 2004).

Many studies have examined the emotional adjustment of parents of children with ASD. These studies have systematically documented that --compared to parents of children with other disorders or with parents of normally developing children-- parents of ASD children have higher levels of stress (Baker et al., 2005; Baker et al., 2003; Belchic, 1996; Cuxart, 1995), anxiety (Baxter et al., 2000; Hastings, 2003; Hastings et al., 2005a; Konstantareas & Homatidis, 1989), and depression (Feldman et al., 2007; Olsson & Hwang, 2002; Phetrasuwan, 2003; Singer, 2006; Smith et al., 2008).

Many studies also suggest that the concomitant behaviour problems in ASD, compared to the severity of the disorder itself, are most strongly associated with stress (Baker et al., 2002; Donenberg & Baker, 1993; Herring et al., 2006; Lecavalier et al., 2006; Tomanik et al., 2004) and with anxiety and depression (Baxter et al., 2000; Blacher, Shapiro et al., 1997; Quine & Pahl, 1991).

Nevertheless, some families, despite having children with severe ASD, have still managed successful psychological adaptation. From this we can infer that the characteristics of autistic children may not be the only factors that influence adaptation. Other types of variables are also involved, including social support, perception of problems and coping strategies. In the next section, we will describe the results of studies that have analysed the influences of these factors on adaptation.

Most of these studies have been carried out using partial analysis of variables. However, it is necessary to adopt a multidimensional and holistic approach to examine the influences of multiple variables simultaneously. In the third section of this chapter, we describe the characteristics of the Double ABCX model of adaptation. This theoretical model has proven to be effective for multi-dimensional analysis of stress and adaptation in families of children with ASD. This is also the theoretical model that our research group has used in the multidimensional analysis of adaptation in parents of children with ASD in the Spanish population, so we also explain the most relevant results of our own investigations.

One factor that has been shown to play a main role in adaptation is the "perception of the problem", evaluated by the variable sense of coherence (SOC). In our research, as in the studies reviewed, SOC plays a protective role against stress and promotes successful adaptation in parents of children with ASD. Given its influence on the outcome of adaptation, we will devote the fourth section of this chapter to describing the SOC and its components, as well as the role it plays in adaptation.

Continuing with the factor "perception of the problem", there has been increasing recognition of the importance of asking more positive questions about the perceptions and experiences of families of children with developmental disabilities (Hastings & Taunt, 2002). This perspective proposes that positive perceptions function as strategies that help families to adapt to or cope with the experiences of raising a child with developmental disabilities. The fifth section of the chapter will present our research on the positive contributions that children with ASD make to the family and the results that we have achieved in this area of research.

In the last section, we reflect on the findings that a positive perspective provides that are relevant to understanding the complexity of the adaptation of families of children with ASD. We also propose possible practical applications of the findings for professionals who work with families of children with ASD.

## 2. Factors involved in adaptation

In research on families of children with ASD, four factors have been shown to be significantly involved in the adaptation of parents: a) characteristics of the child with ASD – namely, the *severity of disorders and behaviour problems*; b) *social support*; c) *perception of problems*; and d) *coping strategies*. Here, we review the most relevant studies that have examined each of these factors and their influences on parent adaptation.

### 2.1 Characteristics of the child

With regard to the *characteristics of the child*, we must note that children with ASD vary greatly in the severity of the core symptoms of the disorders. The *severity of the disorder* varies on a continuum, where some people with ASD are severely affected (e.g., lack interest in others, have no language skills and show a very restricted repertoire of interests), whereas others have only slight impairment (e.g., show concern for others but have no social skills, have formal communication skills but not at a pragmatic level, have good cognitive function but may have specific skills in an area that becomes a stereotyped interest).

Several studies have found that the *severity of the disorder* is positively related to parenting stress (Bebko et al., 1987; Bravo, 2006; Hastings & Johnson, 2001; Kasari & Sigman, 1997;

Konstantareas & Homatidis, 1989; Pozo et al., 2006; Szatmari et al., 1994). That is, a more severe form of ASD is associated with higher levels of parenting stress. One possible explanation for these results is that a child with a severe form of the disorder has less personal autonomy and is more dependent on his or her parents to perform the tasks of daily life (e.g., eating, getting dressed and attending school). Parents of these children say that they have to spend much of their time and energy caring for their child. This makes ASD a potential source of parental stress.

However, the results identify the behavioural problems characteristic of children with ASD – namely, aggressive and self-injurious behaviour – as having more influence on parental stress and family adaptation (Herring et al., 2006; Lecavalier et al., 2006; Tomanik et al., 2004). These behaviours can become threatening to the physical integrity of family members, making home life difficult. Parents need to be constantly alert to try to maintain control of the situation. This constant vigilance can result in a high level of parental stress. This explains the high relevance of behaviour problems to family adaptation.

## 2.2 Social support

As we have seen, the families of children with ASD have to respond to multiple demands. These needs extend to different contexts -family, school and community- and change over time. One factor that has been shown to alleviate parental stress and improve response to the child's needs is *social support* (Bristol, 1984; Dyson, 1997; Sharpley et al., 1997). Dunst et al. (1986) define social support as a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support. Social support may also refer to formal services one receives from professional-based organisations and/or services provided by more loosely structured organisations.

Boyd (2002) presents a critical review of the literature on the relationship between stress and social support in mothers of children with autism. Four groups of studies exist. One group investigates the characteristics of users of social support and of their children that lead parents to seek that support. One of the precursors that lead mothers to seek support is the amount of stress they experience as a result of rearing their child (Sharpley et al., 1997). When mothers are embedded in high-stress situations, they tend to seek social support as a strategy to help them cope. Other studies find an association between challenging child characteristics and a mother's inclination to seek social support (Bristol & Schopler, 1983; Koegel et al., 1992; Sharpley & Bitsika, 1997).

The second group of studies examines the negative effects on mothers of a lack of social support (Gray & Holden, 1992; Konstantareas & Homatidis, 1989; Sanders & Morgan, 1997). The results show that a scarcity of social support is related to higher levels of stress, anxiety, depression and pessimism and less social participation.

A third group of studies analyses the differential effects of two types of support on stress: *informal* and *formal support*. Bristol and Schopler (1983) defined *informal support* as a network that may include the immediate and extended family, friends, neighbours, and other parents of children with disabilities. They defined *formal support* as assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organised group or agency. The results revealed that for mothers of children with autism, informal support appears to be a more effective stress buffer than formal support is.

Finally, the fourth group of studies examines the influence of support on parenting. Dunst et al. (1986) found that parental satisfaction with social support networks was associated with better personal well-being, more positive attitudes about the child, more positive interactions during parent-child play opportunities, and higher scores of their children on developmental tests. In the same way, the work of Raif and Rimmerman (1993) shows that parents who receive social support relate better emotionally to their children and engage in more positive interactions with them.

In summary, social support is a protective factor for the adaptation of parents of children with autism. Families that explain their experience with social support indicate that both the quantity and the quality of social support available to them are important. However, informal support is the more critical source of social support. This form of support provides invaluable emotional and instrumental help to the family. The community and professional support are important too, especially when the service includes family-oriented counselling and educational intervention for the child (Lounds, 2004).

### 2.3 Perception of the problem

The *perception of the problem* is another important factor involved in adaptation. Bristol (1987) assessed mothers' definitions of the stressful situation resulting from their child's disability through a *self-blame* variable – i.e., the degree to which the mother blames herself for her child's disability – and a *catastrophe* variable – i.e., the degree to which the mother perceives her child's disability as a family catastrophe-. The results demonstrated that these two variables are the best predictors of depression and marital satisfaction. Similarly, Saloviita et al. (2003) showed that the most important predictor of parental stress is a negative definition of the situation.

However, other studies have measured positive aspects that protect the family from stress and reduce the impact of the disability, such as: a) *hardiness* (Ben-Zur et al., 2005; Gill & Harris, 1991; Weiss, 2002); b) *self-efficacy* (Hastings & Brown, 2002); c) *ambiguous loss* (Boss, 1988, 1999); and d) *sense of coherence* (Olsson & Hwang, 2002). The *sense of coherence* (SOC) has been shown to be a protective factor in stress research in studies focused on family resilience across different contexts and disorders (McCubbin et al., 1998).

The origin of the SOC concept can be found in the theory of salutogenesis proposed by Antonovsky (1979, 1987). SOC is conceptualised as a "global orientation that expresses the extent to which one has a pervasive, enduring though dynamic feeling of confidence that: 1) the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable (comprehensibility); 2) the resources are available to meet the demands posed by these stimuli (manageability); and 3) these demands are challenges worthy of investment and engagement and that life make sense emotionally" (1987, p.19).

The SOC is used in our research to assess the perception of the problem. The results indicate that it is a very significant variable in the adaptation of parents. Given its importance, we will devote a specific section of this chapter to SOC, explaining its characteristics and role in adaptation.

### 2.4 Coping strategies

Coping, or ways in which people respond to stress, is another factor that influences parental adaptation. Based on general theories of stress and coping (Lazarus & Folkman, 1984) as



well as specific models of family adaptation (Crnic et al., 1983; McCubbin & Patterson, 1983), many studies show the important role played by coping in reducing stress. Folkman and Lazarus (1980) propose that there are two types of coping strategies: a) *problem-focused coping*, which includes cognitive and behavioural problem-solving efforts to alter or manage the source of stress, and b) *emotion-focused coping* strategies that attempt to reduce or manage emotional distress. Individuals usually access more than one coping strategy in managing challenging events and circumstances, and these can involve behavioural as well as cognitive approaches (Nolan et al. 1995).

Different studies have explored the types of strategies that are used by the parents of children with intellectual disabilities. Grant and Whittell (2000) interviewed family members to determine which problem-solving, cognitive and stress reduction coping strategies family they found useful. They found that *problem-solving* strategies are generally considered to be most effective when events and challenges are amenable to change and the person can accomplish the change. "The ability to build on personal experience and expertise" was the most relevant problem-solving strategy mentioned by the interviews. On the other hand, when problem-solving strategies do not work or are perceived to be irrelevant, caregivers may turn to *cognitive coping* in the form of managing meaning. The two most helpful strategies for coping in this category were realising that "there is always someone worse off than yourself" and that "the person you care for is not to blame". The last group of strategies that these authors found was *managing* or *alleviating stress*. Circumstances can arise when neither problem solving nor cognitive reappraisal work, so caregivers have to rely on dealing with the consequences of challenges and the associated stresses.

Coping is theoretically context dependent (Carver et al., 1989). Therefore, both the nature of the stress and the interaction between stressors and the environment should affect the development of coping efforts. Brown (1993) noted that the developmental stages of coping need to be better understood; for example, an initial response involving escape or withdrawal might be a necessary first step toward solving the problem.

Parents of children with ASD are faced with a variety of stressful situations, but many families are able to cope successfully. Some research has examined what kinds of strategies parents use to cope with the demands that accompany raising a child with ASD (Dunn et al., 2001; Hastings et al., 2005b). The findings of this line of research show that parents who adopt *escape-avoidance strategies* to cope with the stresses of raising children with ASD report more stress and mental health problems; in contrast, those using positive reframing strategies report less stress.

In summary, the specific types of coping strategies used by parents of children with ASD affect parental stress and adaptation. Professionals who work with families of children with ASD need to be aware of the coping strategies that parents use to deal with the demands of parenting. The studies show that active avoidance coping appears to be maladaptive and that positive approaches to coping may be adaptive. In this sense, intervention with parents might focus on reducing parents' use of avoidant coping strategies and increasing their use of positive strategies.

Most of the studies cited above carried out only partial analyses of the relations between variables. Only a few studies have examined in a global way the adaptation of parents of children with ASD (Bristol, 1987; Jones & Passey, 2005; Pakenham et al., 2005) or intellectual disabilities (Orr et al., 1991; Saloviita et al., 2003). These studies are based on the Double ABCX model of stress and adaptation (McCubbin & Patterson, 1983) and demonstrate the

model's effectiveness in predicting adaptation. In the next section, we describe the characteristics of the Double ABCX model, the results of research using a multidimensional perspective to study parental adaptation, and our multidimensional studies on stress and family quality of life.

### 3. A multidimensional perspective: The double ABCX model

The Double ABCX model proposes that the adaptation outcome (factor xX) depends on interrelations between several factors: *stressors or characteristics of children* (factor aA); *social support or resources* (factor bB); *perception or definition of the stressor* (factor cC); and *coping strategies* (factor BC). The model postulates that the last three factors could reduce the negative impact of the characteristics of the child on parental adaptation.

Bristol (1987) assessed the factors of the model using the following variables: the severity of the child's handicap and other family stressors; family resources supporting cohesion; social support; the family's definition of the child's handicap; and coping patterns. This author conducted a canonical correlation analysis of data and multiple regressions, and the results showed that informal support and a negative definition of the child's handicap were the strongest predictors of adaptation.

The multiple regression analysis technique has also been used by Jones and Passey (2005) and Pakenham et al. (2005). Coping style and parental locus of control relating to control by the child were the most significant predictors of parental stress in the study by Jones and Passey. Likewise, Pakenham et al. (2005) found that, in support of their predictions, better maternal adjustment was related to higher levels of qualitative social support and emotional approach coping (i.e., positive reinterpretation and seeking social support) and lower levels of child behaviour problems, stress appraisals, and passive avoidant coping.

The multiple regression equations tested by Salovitta et al. (2003) confirm the importance of intervening factors in explaining the stress felt by parents of children with intellectual disabilities. The single most important predictor of parental stress was the definition of the situation. In mothers, this definition was associated with the behavioural problems of the child, whereas in fathers it was connected with the experienced social acceptance of the child.

These studies based on the ABCX model pose a system of data analysis to identify factors that are most predictive of adaptation but fail to analyse the interrelations of these factors in the adaptation model. A more advanced step toward a multidimensional analysis of adaptation is performed by Orr et al. (1991). These authors also discuss the adaptation of parents of children with mental retardation using the Double ABCX model, but, in this case, they use path analysis to examine the relations among the variables in the model. Path analysis allows researchers to make statements about patterns of causation and to identify the direct and indirect effects among the set of variables. Based on the results of their study, these researchers suggest that the actual order of the model could be viewed as a linear chain following an ACBX pattern. That is, the "perception of the problem" is the first step in coping with an event like the birth of a child with mental retardation.

This analysis of the state of the art demonstrates the need to take further steps in the study of the psychological adjustment of parents of children with ASD. Multidimensional analysis allows us to achieve a deeper understanding of the adaptation process by evaluating both the factors themselves and their interrelations. We carry out a study based on the Double ABCX model to analyse maternal stress in a sample of 39 Spanish mothers of children with

ASD (Pozo et al., 2006). We assessed the following variables: *characteristics of child (severity of disorders and behaviour problems)*; *social support*; *the perception of the problem (evaluate by sense of coherence)*; and *stress*. Path analysis was performed using the statistics program AMOS 5 Graphic. This method offers the possibility of providing a global interpretation of the information.

The empirical results of this study (see Fig. 1) demonstrate the utility of the theoretical model for the analysis of stress in mothers of children with ASD.

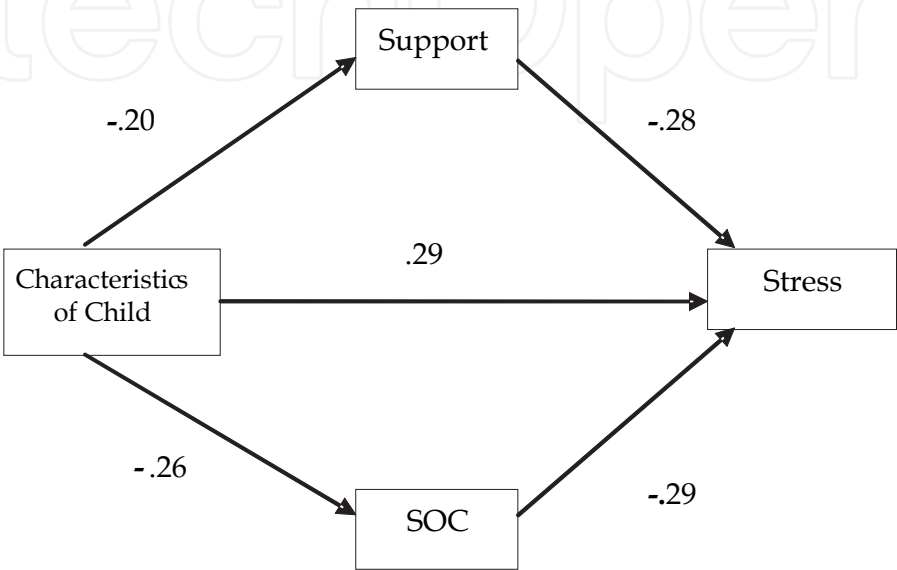


Fig. 1. Stress empirical model and standardized  $\beta$  coefficients

As shown in the figure, the characteristics of the child (*severity of disorder and behaviour problems*) direct and positively affect the level of *maternal stress*. Additionally, the model reveals two indirect ways of influence on stress: 1) the perception of the utility of *social support* in the family; and 2) the perception of the problem, evaluated by a *sense of coherence* (SOC). These variables – *social support* and *sense of coherence* – have a mediating role in the relation between characteristics of children with ASD and parental stress. This result might explain why there are families that despite having children with more *severe autism and behaviour problems* still exhibit better adaptation compared to other families in which the children are less severely affected.

On the other hand, most studies have used negative outcomes, such as stress, anxiety, and depression, to assess adaptation. We consider a positive perspective fundamental to advancing knowledge of adaptation in parents of children with ASD. It is necessary to know what variables are implicated in positive adaptation and to understand their effects on successful adaptation to account for them in designing family interventions to improve adaptation.

Recently, we carried out a multidimensional study to analyse the adaptation model using *family quality of life* as the dependent variable (Pozo, 2010). The participants were 59 mothers of children with ASD aged between 28 and 69 years ( $M = 44.6$ ,  $\delta = 7.9$ ). The children were aged between 4 and 38 years ( $M = 14.2$ ,  $\delta = 7.9$ ); 47 were boys and 12 girls. The distribution frequency in terms of diagnosis was: Autistic Disorder, 43; Asperger’s Syndrome, 1; Rett Syndrome, 5; and PDD-NOS, 10.



Based on the Double ABCX model, we designed a theoretical model of the relations between the variables, which is represented in Figure 2.

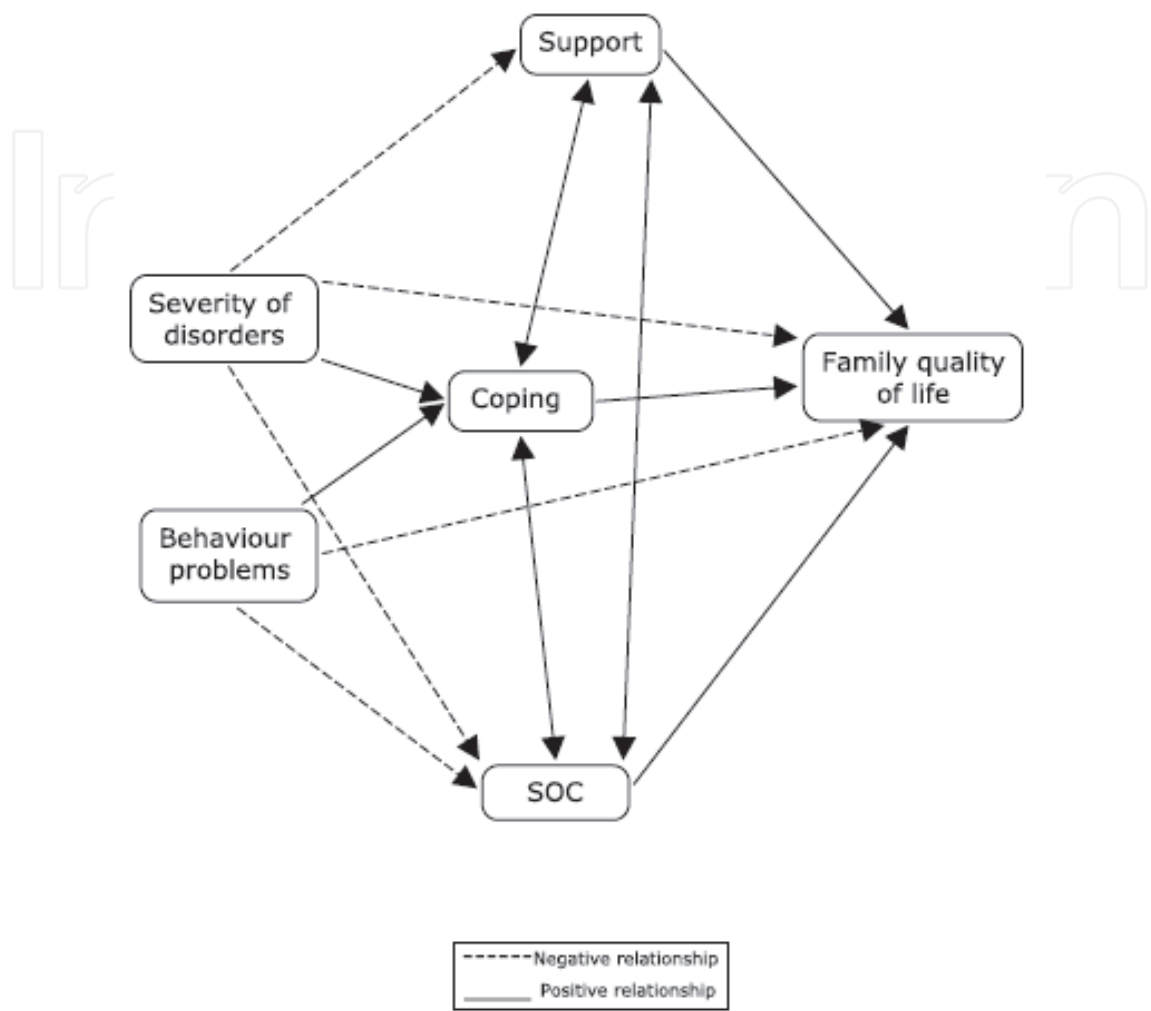


Fig. 2. Theoretical model of family quality of life and interrelationships between variables

Information about the factors and variables was obtained through the following questionnaires:

- Childhood Autism Rating Scale (CARS) (Schopler et al., 1988; adapted to Spanish by García Villamisar and Polaino Llorente, 1992; reliability:  $\alpha = .92$ )
- The Behaviour Problems Inventory (BPI) (Rojahn et al., 2001; reliability:  $\alpha = .89$ )
- Checklist of Supports for Parents of the Handicapped (CSPH) (Bristol, 1979; reliability:  $\alpha = .89$ )
- Sense of Coherence Questionnaire (SOC) (Antonowsky, 1987; reliability:  $\alpha = .90$ )
- Brief Coping Orientation of Problems Experienced (COPE) (Carver, 1997; adapted to Spanish by Crespo & Cruzado, 1997; reliability:  $\alpha = .77$ )
- Family Quality of Life (FQL) (Poston *et al.*, 2003; adapted to Spanish by Sainz et al., 2005; reliability:  $\alpha = .94$ )

Path analysis was carried out with the statistical program AMOS 5 Graphics. In the following figure, we present the empirical model of quality of life in mothers of children with ASD.

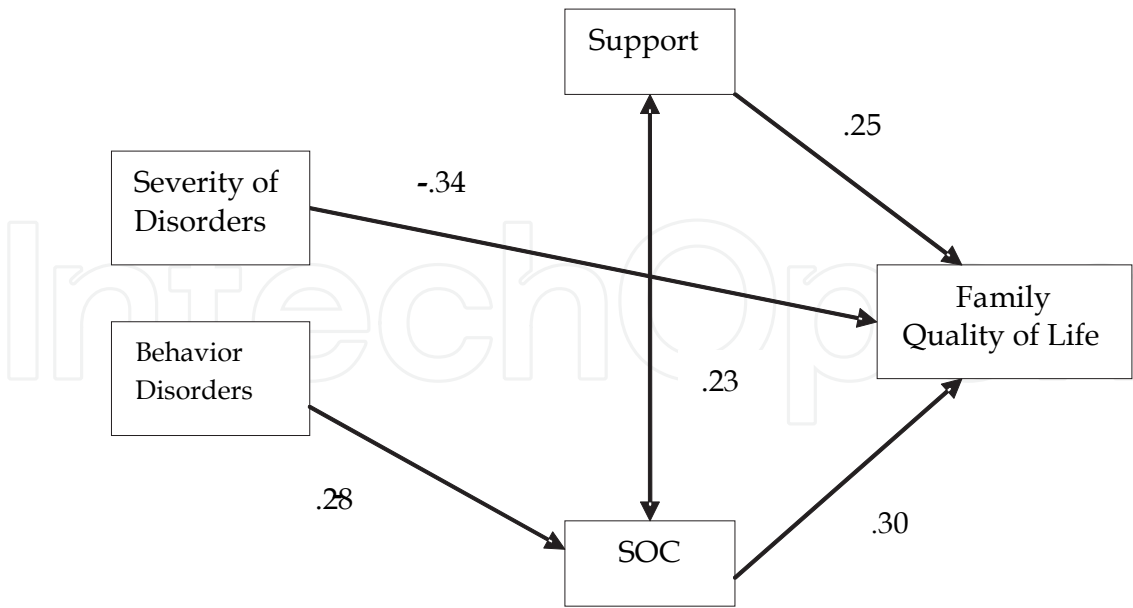


Fig. 3. Family quality of life empirical model and standardized  $\beta$  coefficients

The results show that the empirical models adequately fit the theoretical model, but in a peculiar way. As we can see in Figure 3, *severity of disorders* has a direct and negative relation with family quality of life. That is, mothers who have a child who is more severely affected perceive lower quality of life in the family. More specifically, they might feel fewer positive feeling regarding their family life, and the resources that are readily available to satisfy their needs remain insufficient (i.e., two dimensions of *family quality of life*). On the other hand, *behaviour problems* show an indirect effect on quality of life, specifically through the *sense of coherence* (SOC). Thus, the effects of behaviour problems on adaptation are moderated by the level of SOC in mothers. Mothers with a high level of SOC probably perceive that the *behaviour problems* of the child are more controllable and less threatening than would a mother with lower levels of SOC. With regard to *social support*, mothers who perceive that they have adequate social support to cope with the demands of caring for their children are likely to report a better family quality of life. In summary, in all of the existing studies of adaptation in parents of children with autism, the perception of the problem is the most relevant predictor of adaptation. Our studies demonstrate that SOC plays a fundamental role in adaptation as a mediator of the effects of stress and family quality of life. The next section describes the SOC and explains its influence on adaptation.

4. The sense of coherence as a mediator and predictor variable

Antonowsky (1979) sought to explain the relation between life stresses and health in the theory of salutogenesis by what he calls the *sense of coherence* (SOC). SOC was defined as: “a global orientation that expresses the extent to which one has a pervasive, enduring, though dynamic, feeling of confidence that one’s internal and external environments are predictable and that there is a high probability that things will work out as well as can reasonably be expected” (p. 132).

The salutogenetic perspective proposed by Antonowsky (1987) suggests that SOC enables people to resolve tension in a health-promoting manner, to reflect about their external and internal resources, to identify and mobilise them, and to promote effective coping by finding solutions.

SOC is conceived as a personality characteristic or coping style, an enduring tendency to see one's life space as more or less orderly, predictable, and manageable. This theoretical model suggests that individuals develop a generalised way of looking at the world as more or less coherent. This sense of coherence tentatively appears in childhood; it becomes more definitive during adolescence, becoming fully developed around age 30 (Antonowsky & Sagy, 1986).

The SOC consists of three components. The first component is a cognitive aspect called comprehensibility. It is defined as the ability of the family or the individual to understand life situations and give them some order and structure. The second component is manageability, which emphasises the emotional aspect. It refers to the ability to handle or respond to situational demands or the feeling that one is capable of obtaining the necessary resources to do so. Finally, the component that corresponds to the motivational aspect is the meaning, or sense, which refers to the extent that one feels that life makes sense. People with high scores on this component see problems as challenges and commitments that are worth the effort necessary to address them.

A significant amount of research has investigated the SOC, especially its contribution to the development and maintenance of health from salutogenesis theory. Eriksson and Lindström (2006) review 25 years of research (458 scientific publications) on the relation between the SOC and health. Their analysis and conclusions show that SOC is strongly related to health, especially mental health. In general, stronger SOC is related to better perceived health. This relation is manifested in study populations regardless of age, sex, ethnicity or nationality. SOC alone does not explain overall health but is an important contributor to the development and maintenance of health. SOC seems to play a main, mediating role in the explanation of health. Furthermore, the SOC seems to be able to predict health. From a psychological perspective, research has characterised its relation to psychological well-being (Cohen & Dekel, 2000; Pallant & Lae, 2002; Sagy et al., 1990) and its inverse relation with anxiety (Antonovsky & Sagy, 1986).

SOC is conceptualised as a coping mechanism characterised by the tendency to see life as predictable and manageable. Thus, a person with a high SOC is less likely to perceive a situation as threatening and anxiety arousing compared to a person with a weak SOC. Family life is filled with stressors, even more so for the parents of a child with ASD, but some parents adjust well and become empowered.

Stressors can be either acute or chronic, and the two forms have different relations with the SOC (Antonowsky, 1987). An acute stressor is discrete and time limited. Individual differences in SOC levels predict individual differences in coping with acute stressors. A person with a weak SOC is more vulnerable to the stressor. Knowledge of the diagnosis that one's child has ASD can be characterised as an acute stressor. Therefore, the SOC level of the parent prior to the diagnosis may determine how he or she deals with the impact of the news and adjusts to life with the child. High-SOC parents of children with ASD may perceive their situation as a challenge and assume that they can adapt to the demands. The underlying confidence that things will work out and that one has the resources to cope is a relevant strength.

The results of studies show that SOC acts as a mediator in the relation between autistic symptom severity and parenting stress (Mak et al., 2007; Pozo et al., 2006) and in the relation between children's behavioural problems and parents' perceptions of family quality of life (Pozo, 2010).

A chronic stressor is a generalised and long-lasting life condition or characteristic that is embedded in the life of a person. Antonowsky (1993) found evidence that women with certain chronic illnesses have very low levels of SOC. Olsson & Hwang (2002) raised the interesting question of whether parenting a child with autism could become a chronic stressor that influences the parent's SOC level negatively over time. The birth or the diagnosis of a child with disabilities can be considered an acute stressor, but an acute stressor can alter a family's life in such a way that it becomes a chronic stressor. They found that mothers of children with autism have lower SOC levels than mothers of children with intellectual disability but without autism, who, in turn, had lower SOC levels than control mothers. Fathers' SOC scores did not differ significantly among the three groups. Their hypothesis, i.e., that the presence in a family of a child with an intellectual disability is a chronic stressor that influences the parents' SOC level negatively over time, was only partly supported, since no relation was found between the age of the child and SOC levels in parents of children with intellectual disability or autism.

The SOC, as a stable trait, may be adversely affected by crisis situations, but over time it can be reset and restored to its previous values (Antonowsky, 1987). The impact of a child's diagnosis of autism and the first and most difficult experiences of facing life with a child with intellectual disabilities and behavioural problems are inevitably acute stressors that can adversely affect the SOC. However, we also think that the passage of time and the progressive increase in control of the situation may allow improved SOC. The parents improve the perception that the course of life is structured, predictable, and explicable, that resources are available to meet the demands, and that these demands are challenges worthy of investment and engagement. Data from a longitudinal study of 21 mothers of children with ASD support this hypothesis (Pozo, 2010). The scores for this group of mothers on the SOC scale (Antonowsky, 1987) in two times of measurement, with an interval of four and half years, reflected a statistically significant increase due to improvements in two of the components of SOC: comprehensibility and manageability. The meaning or significance dimension is stable between the two measurement points. These results support not only the mediating or modulating role of SOC (Pozo et al., 2006; Pozo, 2010) but also the possibility of regaining higher levels of manageability and comprehensibility perception and their protective benefits.

In summary, studies on the SOC in the broad health context and specifically in parents of children with ASD and the results of empirical studies suggest that the concept of SOC, its theoretical framework and the body of related research are valuable tools for understanding the psychological adjustment of parents of children with ASD.

## 5. Positive contributions to the family

Until the late 1980s, family and disability studies focused on the analysis of the negative effects of a child's disorder and its consequences in the family. Empirical research on the positive contributions of a disabled child to the family was very rare. However, parents' narratives about their relationships with their disabled children have always included positive aspects. Thus, Mullins (1987), in a review of 60 books written by parents of disabled

children, found that parents inevitably mention negative aspects of their lives (e.g., demands, needs, anxiety, stress), but also appear to be positive (e.g., positive feelings, personal growth, family strength).

One of the most significant studies on the positive contributions of children with disabilities in the family was conducted by Behr et al. (1992). This research served as the basis for the construction of the four scales that constitute the Kansas Inventory of Parental Perceptions (KIPP). One of the four scales is the "Scale of Positive Contributions". Interviews were conducted with 28 families in which parents asked to describe explicitly the positive contributions of living with a disabled child. The aim of this study was to identify the categories that define the positive contributions that parents report. A qualitative analysis of the interviews revealed 16 categories of positive perceptions that, after conducting a factor analysis, were finally grouped into 5 factors. Further validation in a sample of 1,262 families of children with disabilities revealed four additional factors that were not identified in the previous phase. Thus, the "Positive Contributions" Scale is composed of 50 items corresponding to 9 dimensions. A more recent study (Hastings, Allen, McDermott and Still, 2002) applying this scale found only 3 different factors describing disabled children's positive contributions: a) Happiness and Fulfilment; b) Strength and Family Closeness; and c) Personal Growth and Maturity. The factor structure was reduced, but the positive perceptions that parents reported in the different studies showed a pattern of systematic categories.

A few interesting studies explore the possible influence of positive perceptions of family adaptation through their relation with variables such as stress and family well-being. These studies show that positive perceptions reduce the negative impact that disability can have on the family and that these relationships can be modulated further by individual variables, such as gender of the parents (Hastings and Taunt, 2002).

Most studies have focused on disability in general. Targeted research is needed on the perception of positive contributions by parents of children with ASD and the influence of these contributions on the parents' psychological adjustment. With this objective in mind, we conducted an empirical study in a sample of Spanish families with a child affected by ASD. We wanted to study the influence of *perceptions of positive contributions* on family adaptation to the problems posed by ASD through its relations with *family quality of life, anxiety, depression* and *stress*. We were also interested in determining whether there were significant differences between mothers and fathers in positive perceptions as a contributor to adjustment.

Although there is no explicit theory on positive perceptions, both stress and coping theory and the theory of cognitive adaptation propose that positive perceptions function as resources and strategies that help families to adapt to the challenge of caring for a disabled child. Therefore, we formulated the hypothesis that the parents' perception of positive contributions would have inverse correlations with depression, anxiety and stress and a positive correlation with quality of family life (Pozo et al, 2010).

The study involved 24 fathers and 33 mothers aged between 36 and 78 years ( $M = 45.79$ ,  $\delta = 8.39$ ). The children were aged between 6 and 32 years ( $M = 13.85$ ,  $\delta = 7.83$ ); 24 were boys and 11 girls. The distribution in terms of diagnosis was: Autistic Disorder, 24; Asperger's Syndrome, 2; Rett Syndrome, 1; disintegrative disorder, 1; and PDD-NOS, 7.

The Positive Contribution Scale (Behr et al., 1992), discussed earlier, was used for the evaluation of the perception of positive contributions. This is a 50-item scale with 9 subscales, although our study used only 3 dimensions, as proposed by Hastings et al. (2002).



The scales used to assess the variables related to family adaptation and reliability results obtained in the study were as follows:

- Family Quality of Life (FQL) (Poston *et al.*, 2003; adapted to Spanish by Sainz *et al.*, 2005). Reliability ( $\alpha = .95$ ).
- The Hospital Anxiety and Depression Scale (HADS) (Zigmon & Snaith, 1983; adapted to Spanish by Tejero *et al.*, 1986). Reliability ( $\alpha = .75$ ).
- Parenting Stress Index (PSI) (Abidin, 1995; adapted to Spanish by Pozo, 2010). Reliability ( $\alpha = .82$ ).

T-tests were applied to compare the means both of the adjustment variables and of the measures of positive perceptions between mothers and fathers. The results are shown in Table I

		N	M	t
Total Positive Contribution (PC)	father	24	123.83	2.01*
	mother	33	131.64	
PC Happiness	father	24	16.71	.95
	mother	33	17.49	
PC Strength	father	24	19.62	3.01*
	mother	33	21.93	
PC Growth	father	24	17.45	.32
	mother	33	17.75	
Family Quality of Life Satisfaction	father	24	88.16	.53
	mother	33	85.84	
Family Quality of Life Importance	father	24	96.29	.59
	mother	33	98.93	
Anxiety	father	24	6.08	2.03*
	mother	33	7.51	
Depression	father	24	4.66	.92
	mother	33	5.39	
Stress	father	24	105.75	.64
	mother	33	108.36	

Table 1. Positive contributions and adaptation: mean differences between mothers and fathers

The first notable result is that the degree of *stress* in both fathers ( $M = 105.75$ ) and mothers ( $M = 108.36$ ) achieved clinically significant levels (values above 90), although there were no significant differences between mothers and fathers in this variable. The only adaptation variable in which there are significant gender differences is anxiety ( $t= 2.03$ ,  $p<0.05$ ). The mothers have higher levels of anxiety compared to the fathers. With regard to positive perceptions, there are significant differences in the Positive Contribution Scale Total ( $t = 2.01$ ,  $p <0.05$ ) and the subscale of Strength and Family Closeness ( $t = 3.01$ ,  $p <0.05$ ), with the mothers scoring higher on both measures.

To accomplish the second objective, namely, to ascertain the relation of the positive contributions to family adaptation, we proceeded to an analysis of correlations using the Pearson coefficient (see Table 2).

The results show that, for the fathers, the subscale of Strength and Family Closeness is positively and significantly related to Quality of Family Life in two dimensions: Satisfaction ( $r = .43, p < 0.01$ ) and Importance ( $r = .47, p < 0.01$ ). In mothers, only the Personal Growth and Maturity subscale shows a significant relationship with the *anxiety* variable ( $r = -.55, p < 0.01$ ), with a negative sign. That is, those mothers who believe that caring for their child will bring them feelings of personal growth and maturity will face situations more calmly, thus reducing their level of anxiety about the demands and challenges posed by their situation.

	Total		Happiness		Strenght		Growth	
	father	mother	father	mother	father	mother	father	mother
FQL Satisfaction	.18	.33	-.02	.16	<b>.43**</b>	.26	-.29	.24
FQL Importance	.27	.10	-.03	.05	<b>.47**</b>	.27	-.19	-.22
Anxiety	.29	-.23	.22	-.25	.21	.04	.23	<b>-.55**</b>
Depression	-.09	-.16	-.15	.12	-.15	-.17	-.07	-.27
Stress	-.08	-.31	-.23	-.26	-.19	-.18	.28	-.33

Table 2. Matrix correlations between Positive Contributions scales and adaptation variables

In summary, these data show that the perception of positive contributions is relevant to the psychological adjustment of parents. Parental perception of Strength and Family Closeness shows a close relation with perception of Quality of Family Life in the two dimensions of Satisfaction and Importance. The fathers’ perception of positive contributions does not affect their mental health, as manifested by depression, stress or anxiety. However, the level of perceived positive contributions and the role that perceived positive contributions play in the process of adaptation are different for fathers and mothers. Mothers perceive more positive contributions compared to fathers. The mothers also have higher levels of anxiety. At the same time, their capacity for the perception of positive contributions, particularly their perception of Personal Growth and Maturity, is negatively related to their levels of anxiety ( $r = -.55, p < 0.01$ ). These results are not contradictory.

In general, mothers are more involved than fathers are in the care of a child with ASD. In that sense, mothers are more exposed to the challenges and demands of raising the child and show higher levels of anxiety. At the same time, mothers may have more opportunities to observe positive changes in the child and to experience personal growth associated with overcoming the daily challenges of organising the child’s life and responding to the needs of the child. We could also say that the perception of the positive contributions plays a protective role that is especially relevant to psychological adaptation in the case of mothers.

The study results reflect the relevance of research on the positive aspects of raising a child with ASD and underline the need for further research. The findings also show that the Positive Contribution Scale can be a useful tool to explore positive perceptions in families of children with ASD and to identify specific actions to increase positive perceptions.

## 6. Implications for intervention

Despite their limitations, we believe that these studies, especially the multidimensional perspective, provide new data that will help researchers and clinicians to better understand the complexity of the adaptation of families of children with ASD. These findings may be directly applicable to the planning of objectives and strategies for professionals working with families of children with ASD. Two major aspects stand out as possible points for intervention: the importance of the perception of positive contributions and the protective role of the SOC and its resilience to chronic stress.

When the adjustment of families of children with ASD is studied, the focus is often on negative effects, while the positive effects are ignored. From a prevention and intervention perspective, it is important to understand what the negative effects are to provide family members with adequate strategies and techniques for reducing or counteracting them. However, the positive aspects of having a child with ASD are equally important to consider. Some parents who are initially depressed with their child's diagnosis of autism recover and cope effectively with the situation. Why are some families insulated from the more adverse effects of stress and able to grow and become empowered?

The results of these empirical studies support the important role other authors have proposed for protective factors in their models of family adaptation. The family adaptation model described by Lounds (2004) proposes that three groups of factors exert important influences on family functioning: historical factors, family coping resources and family social support. She places special emphasis on family coping resources as protective factors. Protective factors can serve to increase family resiliency and to reduce the potential adverse effects of the challenges on the family. These protective factors may be improved with appropriate intervention. These resources include, among others, parenting knowledge and skills, problem-solving skills, organisational skills and optimism.

The challenges confronting families of children with ASD are quite varied, and in the long term, so are the organisational abilities, priorities and routines, and problem-solving skills that will be critical to family survival and a feeling of control of their lives. Psychologists and counsellors often teach these skills to their clients. Families that do not have well-developed organisational skills can acquire them with counselling and practice. However, what about optimism? What about positive perceptions?

Family members' attitudes about the situation may be more important than the concrete challenges that the family faces. Positive attitudes lead to hope and other positive emotions. Hasting and Johnson (2001) found that parents of children with autism who were able to positively reframe challenging events were less likely to report being depressed. We found that the mothers of children with ASD who reported experiencing personal growth and maturity as a result of their life with a child with autism experience lower anxiety levels. Parents' reports of their children's positive contributions are also related to their adaptation, particularly to the perception of quality of family life.

Can psychologists, teachers, medical personnel, and service providers help parents to discover and appreciate the positive contributions that their children with autism bring to their lives?

The work that accompanies the development of a child with ASD will always include goals to achieve, but parents must learn to value milestones that have already been reached. Communication educators, service providers, and psychologists should not focus only on problems and difficulties when interacting with parents but should always leave

time to highlight the positive aspects of the child's development, including his or her strengths and improvements. For example, consider the dynamics of communication between the parents and the child's school. The communication system is based on requests for meetings with parents when there are problems or difficulties in inclusive education. This system will surely help solve the problems, but it will not encourage the development of positive perceptions among parents. On the contrary, if the school has a good communication protocol that feeds positive information back to parents, trains teachers on the importance of communication with parents and seeks balance in the parent meetings between a summary of the child's progress and a discussion of his or her challenges, great benefits to parents will result. Parents whose children attend such schools report higher perceived school support and less anxiety about their decisions on the education of their children (Babío, 2009).

It should be kept in mind that the perception of positive contributions to the psychological adjustment of parents can lead clinicians, teachers, and others who interact with children with ASD to modulate their strategies and forms of communication to provide opportunities and content that promote positive perceptions.

As we have seen in previous sections, one of the factors that are relevant to the explanation of psychological adaptation in parents is the perception of the problem. Both the literature review and the results of the studies presented here emphasise the protective role of SOC. The SOC works as a global mechanism that modulates the impact of child behaviour problems and facilitates the selection of the best coping strategies. The SOC protects the psychological and social well-being of parents. This demonstrated importance raises the question of how professionals can strengthen parents' SOC.

Antonovsky (1993), who first developed the concept of SOC, raises the same question and another that is no less important: do we have a criterion for avoiding strategies that may weaken the SOC? To answer these questions, the author lays out some key principles:

1. It is important to understand that "to optimize the chances of successful coping with a stressor one must believe that one *understands* the problem and that one has at one's disposal the *resources* that are needed, and one must *wish* to cope with the problem" (p. 117).
2. It is essential to understand that a strong SOC is not a particular coping style. Potential stressors in life are so many and so varied that there is no pattern of coping that fits all of them: "What the person with a strong SOC does is to select the particular coping strategy that seems most appropriate to deal with the stressor being confronted" (Antonovsky, 1987, p. 138). For coping to be successful, it is important to respond appropriately given the nature of the stressor. It is therefore crucial that parents have a wide repertoire of coping strategies and the flexibility to choose and implement the most appropriate strategy for each challenge at a given time.
3. The SOC has three components: comprehensibility, manageability and meaningfulness. Antonovsky sees meaningfulness as primary. Do the parents see their child's developmental disability as a burden or challenge? This is the motivational core of the matter. Do they wish to cope? This is a critical question. Without motivation, providing information or support is unlikely to be useful. If parents start by seeing coping as possible and desirable, increasing comprehensibility and manageability is more likely.

In conclusion, our first challenge as professionals should be to help parents of children with ASD to overcome their hopelessness and maintain the motivation and desire to cope with the challenges of parenting a child with ASD. On this basis, we can help strengthen the comprehensibility and the manageability of the situation for parents.

Providing parents with the necessary information about the disorder has always made sense, but the present results on the role of SOC as a protective variable argue for even more attention to be paid to this need. Adequate and well-managed information helps parents to understand the problem and to have a perception of greater control and ability to manage the situation. Parents who know more about autism and its treatment and, overall, how to parent a child with autism, will be better able to adjust their expectations about the development of the child as well as their own feelings of well-being and competency. Professionals can help to strengthen parents' SOC by identifying strengths and internal and external resources at their disposal. They can help parents to make use of these resources despite difficult circumstances. Social support from family, friends, institutions, associations or support groups can make life more manageable and understandable. Social participation by parents is important and should be a goal in itself.

As stated by Meyer (1993), a natural response to a crisis in the family is the desire to do something to improve the situation. Early intervention programs usually involve mothers, but other family members may not be included. Without opportunities to contribute to ameliorating the crisis, family members may feel powerless. By contrast, programs that provide family members with concrete ways of improving the family's situation may promote mental well-being. By providing family members with opportunities for support and information, fathers, siblings and grandparents can increase their sense of control over the crisis. Moreover, the involvement of those members of the family, especially fathers, will have reverberating positive effects on mothers.

Providing parents with a wide repertoire of coping strategies -cognitive, emotional and instrumental - and developing the flexibility and the understanding needed to choose and implement the most appropriate strategy to tackle each challenge are also important objectives of professional interventions to help families of children with ASD.

## 7. Conclusions

In conclusion, we want to emphasise that the families of children with ASD can be helped to meet the child's needs in appropriate ways. Moreover, in this process of adaptation, some parents have an experience of growth and maturity that empowers them. Research on adaptation processes can help to identify risks and protective factors. In this sense, the multidimensional perspective has proven particularly suitable to allow analysis not only of the weights of the various factors but also of the relationship dynamics that explain the psychological adjustment of parents. It is important to identify the needs and difficulties involved in caring for children with ASD to provide or develop the actions necessary for support. However, it is equally important to identify the positive contributions to family life of a person affected by ASD and to study family adaptation from a positive perspective, looking for factors promoting psychological well-being and enhancing the perceived quality of family life. Research in this area is only beginning, and much future work is needed.



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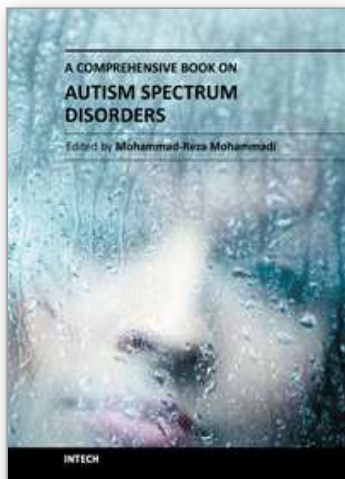
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## **A Comprehensive Book on Autism Spectrum Disorders**

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The aim of the book is to serve for clinical, practical, basic and scholarly practices. In twentyfive chapters it covers the most important topics related to Autism Spectrum Disorders in the efficient way and aims to be useful for health professionals in training or clinicians seeking an update. Different people with autism can have very different symptoms.Â Autism is considered to be a “spectrum” disorder, a group of disorders with similar features. Some people may experience merely mild disturbances, while the others have very serious symptoms. This book is aimed to be used as a textbook for child and adolescent psychiatry fellowship training and will serve as a reference for practicing psychologists, child and adolescent psychiatrists, general psychiatrists, pediatricians, child neurologists, nurses, social workers and family physicians. A free access to the full-text electronic version of the book via Intech reading platform at <http://www.intechweb.org> is a great bonus.

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