

# Needs Assessment Resource Document

**Integrative Parents' Autism Training**

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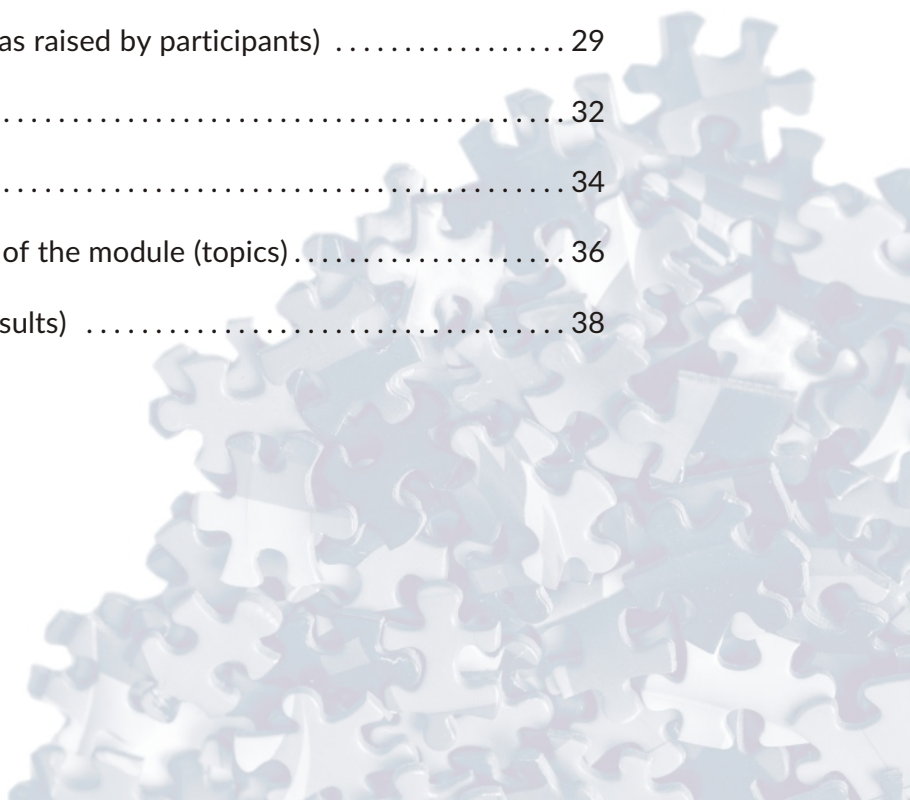
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## IPAT Needs Assessment Resource Document

### Literature Review

#### Autism and parents

Autistic spectrum disorder (ASD) is a neurodevelopmental disorder where the individual exhibits restrictive and repetitive patterns of behaviours and interests, as well as deficits in the areas of social communication and interaction. The symptoms of the disorder are exhibited from the early years of life and can affect many areas of daily functioning. The level of functioning of each individual differs significantly with symptoms ranging from severe cognitive and social deficits to more subtle difficulties in social communication and interaction. The etiology of the disorder is very complex and heterogeneous, and it has been shown to include the interplay between genetic, epigenetic and environmental factors. The prevalence of the disorder has shown significant increases in the last decades with estimates showing great variance due to methodological differences in case detection. These increases are most often attributed to the broadening to the diagnostic criteria, increased awareness of both professionals and parents and increased availability of services. Chiarotti and Venerosi (2020) did a review of worldwide prevalence estimates since 2014 and showed that estimates can range from as low as 0.8 in 1000 to as high as 93 in 1000, depending on the methodology used and the source of the data. Nevertheless, most of the recent studies identify a prevalence ranging between 0.8 and 1.5%. Although the reasons for the increase in prevalence are not clear it is unmistakable that ASD have become a major public health issue.

The difficulties that children who have ASD face are significant and impact the quality of life of both themselves and the whole of the family. According to the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (American Psychiatric Association, 2013) the difficulties in social communication and interaction involve deficits in social-emotional reciprocity, deficits in nonverbal communicative behaviors used for social interaction, and deficits in developing and maintaining relationships. The difficulties can range, for example, from complete lack of speech and acknowledgment of others in the social environment to difficulties in conversation and/or initiating and sustaining a social

interaction, reduced sharing of interests and emotions, difficulties in making friends and sharing imaginative play. The restricted and repetitive patterns of behaviour, activities and interests may involve stereotyped or repetitive speech, motor movements, or use of objects; excessive adherence to routines, ritualized patterns of behavior, or excessive resistance to change; highly restricted and fixated interests; and hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment.

Although not acknowledged as core symptoms of the disorder children with ASD often have co-existing difficulties that can further affect the everyday living and wellbeing of both themselves and their family. For example, it has been found that there is an increased prevalence of behavioral and emotional problems, such as attention problems, anxiety, depression and withdrawal, self-injury and aggression (Kaat & Lecavalier, 2013; Maskey, et al. 2013; Ooi et al., 2011). Also, epilepsy and intellectual disability. Moreover, many studies as well as clinical reports, report increased difficulties in areas such as sleeping, eating and toileting (Margari, et al. 2020; Maskey et al., 2013; Oyane & Bjorvatn, 2005).

In order to address these difficulties individuals with ASD are involved in many different types of therapies and receive support in many areas of their life, both in their home, the school, and the community. Most individuals depending on their level of functioning will need to be supported one way or the other throughout their life with their needs changing as they pass different developmental stages. Moreover, the range of interventions available for parents to choose from is vast with some of the most common being intensive behavioral therapies, developmental social pragmatic interventions, individualized education plans, speech therapy, occupational therapy, and special education classes. There are also many other complementary forms of evidence-based effective therapy such as music therapy, therapeutic horse riding, social skills groups, therapeutic swimming, medication, sensory integration therapy, play therapy, cognitive behavioural therapy etc.

Parents of children with ASD therefore face many challenges and have to adopt many different roles in their efforts to help their children integrate to the community and live a happy and fulfilling life. More specifically parents of children with ASD are faced with the difficulties of getting an official diagnosis for their children, a process that can be time consuming and quite stressful both in terms of getting to terms with what such a diagnosis means for their children, as well as getting a clear and specific diagnosis by professionals, a

process which is not always as clear cut as one would expect. Smith-Young and her colleagues (2019) talk about three main phases in accessing diagnostic and treatment services for their children that start with first noticing suspected behaviours and searching for assessment, continues with receiving the diagnosis, accessing treatment services and finally pondering the future, reflecting on the past and making recommendations. Similarly DePape and Lindsay (2014) talk about six main themes in parents' experiences of caring for a child with ASD that consist of: pre-diagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward.

After the initial process of diagnosis the parents have to navigate through the vast numbers of interventions available and, according to Gentles and his colleagues (2019), they first have to understand and accept that their child has autism, then go into high gear by really learning about and trying different treatment approaches and then finally ease off when the children get a little bit older. Apart from having to fight their way through the process of getting a diagnosis, educating themselves, accepting that the child has autism and choosing the right intervention(s) for their child the parent also has to act as an advocate for their child's rights and access to services and community inclusion. Boshoff and colleagues (2016) illustrate both the lifelong challenging nature of having to become an advocate for ones' child as well as the associated personal and societal benefits it can generate, since advocacy can act as a parental coping strategy and also provide a means for overcoming the isolation that often families with children who have ASD experience.

Parents of children with ASD have also contributed significantly to the expert understanding of autism not only by acting as advocates seeking to obtain better treatment options for their children, but also as acute observers of their child's needs and characteristics and promoting research in the course of investigating promising interventions (Silverman and Brosco, 2007). More and more research shows the importance of increasing the focus within clinical settings on parent-defined concerns and working towards a collaborative model of service development between parents and professionals (Clark & Adams, 2020; Gentles et al., 2019; Majoney & Wiggers, 2077; Silverman and Brosco, 2007).

The difficulties that children with ASD experience also mean that parents have to support them in many areas of everyday living. More specifically, parents have to deal with health

issues as well as emotional and behavioural problems, they need to provide opportunities for building peer relations and community inclusion, provide practical support with everyday life deficits and support their engagement in recreational activities. In addition to the above roles parents play, more and more interventions include them as co-therapists and stress the importance of parent-mediated interventions and parent training. In these interventions parents are the agent of change and they are trained by professionals to promote specific skill acquisition as well as deal with behaviour problems of their children. They can act as primary or complementary interventions.

These interventions are especially valuable not only because they have been shown to provide significant improvements in skill acquisition and reduction of problem behaviours, but also because parents are usually the most significant social relationship for their children and therefore can act as the greatest motivation for interaction and communication. Moreover, children spent significantly more time with their parents than with teachers or other professionals and therefore provide increased opportunities for skill acquisitions and because these opportunities take place in their everyday life they are the ideal context to generalise skills and help long-term maintenance of treatment gains. Finally, parent-mediated interventions can help with cost effectiveness issues of treatments although it has been shown that they can't act as a replacement of more intense interventions plans as early diagnosis and intensity of treatment still play a significant role in treatment gains (Rogers et al., 2012).

For example, parent training has been found to reduce disruptive behaviour in children whilst improving the sense of parental competence, reducing parental strain and parental stress (Iadarola et al., 2018). Similar results have been found by Bradshaw et al. (2018) who showed improvements in child disruptive behaviours, parental stress and strain, parental competence and mental health, as well as daily living skills of children. Postorino and colleagues (2017) also show that parent training can be efficient in reducing disruptive behaviour in children with ASD in a systematic review and meta-analysis of eight studies, although there was significant heterogeneity in the effect of the training between studies.

Oono and colleagues (2013) reviewed studies to assess the effectiveness of parent-mediated early intervention on both children and parents and found that although there were no significant gains in most of the primary outcomes assessed, with the exception of

child language comprehension and reduction in autism severity, there was clear positive change in patterns of parent-child interaction (e.g., shared attention, parent synchrony). In addition, Pickles and colleagues (2016) investigated the long term effects of a parent-mediated social communication therapy for young children with ASD and found that there was an overall reduction in symptom severity and child initiations in communication even after five years of completion of the initial intervention. There were, however, no differences between groups in regards to scores in an expressive-receptive language composite.

In addition to more and more studies showing increased effectiveness of parent-mediated interventions on child symptoms as well as parental adjustment (Estes et al., 2014) one also needs to consider the importance of focusing on supporting parents in their attempts to communicate and interact with their children. Although we clearly now understand that ASD is not caused by distant and 'cold' parenting rather than complex genetic factors, parenting behaviours still play a very important role in the development of children with ASD just as in the case of typically developing children. This becomes even more obvious when one considers the child's difficulties in interacting and socially communicating with his/her environment and the detrimental effect these difficulties can have on parenting behaviour itself. In a review examining parental contributions to the development of children with ASD Crowell and colleagues (2019) provide evidence that parental sensitivity and synchronization can enhance children's development in a number of domains. Additionally, Teague and colleagues (2018) highlight the bidirectional nature of parenting practices and attachment in children with ASD.

### Parents' emotional wellbeing

The specific characteristics and needs of autistic children, mentioned above, impacts their parents emotional wellbeing in a multi-factorial and non-linear way. As above, it usually begins even before the awareness of autism. Those traits and needs may be noticed before engaging to a diagnostic procedure, which it itself a long and difficult process itself that is characterized by its own qualities, difficulties and challenges (Zuckerman, Lindly & Sinche, 2015; Lappé et al, 2018; DesChamps, Ibañez, Edmunds, Dick & Stone, 2020).



The field of research on parents of autistic individuals is still growing (Nordahl-Hansen, Hart & Øien, 2018). At its first steps it was mostly quantitative and aimed at the evaluation of the negative emotional impact of the characteristics of autism upon the family, such as the presence of parental stress and other concurrent psychological problems. A general observation was that parents of autistic children suffered from higher psychological distress, frequently investigated in the form of 'parental stress, anxiety and depression', compared to parents of typically developing children (McKinney & Peterson, 1987; Bitsika & Sharpley, 2004; Bonis, 2016; Saccà, Cavallini & Cavallini, 2019; DesChamps et al., 2020), children with other neurodevelopmental conditions and children with other mental or physical disabilities (Bouma & Schweitser, 1990; Estes et al., 2014; Bonis, 2016; Picardi et al., 2019; Pastor-Cerezuela, Fernández-Andrés, Pérez-Molina & Tijerras-Iborra, 2020). Moreover, despite the fact that research outside typical western society is still evolving (Nordahl-Hansen, Hart & Øien, 2018), the findings from other cultural backgrounds, such as Turkish, Egyptian and Chinese (Çelimli, 2009; Aly, Ibrahim, Ashkar & Bayomi Soad Sayed, 2013; Zhou, Liu, Xiong & Xu, 2019) have also found persistently higher parental stress, anxiety or depression in this group.

Yet the gradual recognition of the contribution of subjective viewpoints to the understanding of a psychological or social phenomenon in social research has recently led to the design and implementation of qualitative studies of parents of autistic individuals too, which seem to be offering them the opportunity for their voices to be heard differently and have led to interesting and frequently alternative findings to those of the past, such as that autism and its diagnosis could be a positive experience (Gentles, Nicholas, Jack, McKibbin & Szatmari, 2020). These recent findings are contrasted to long-held beliefs, such as that the period following diagnosis is similar to a process of mourning or grieving (Rasmussen, 2000; Wong, 2005; Russel & Norwich, 2012), an approach whose universality might have to be revisited, in view of recent findings (Gentles et al., 2020).

Similarly, an overall shift has been noted in the area that research is currently focusing upon, that is, from the aforementioned negative psychological impact and emotional difficulties to a broader, more holistic and less negatively connotated characteristic in families, like the parents' quality of life. It is worth investigating what new can this approach reveal with regards to the concerns of parents about their autistic children and how can this

inform and reform the content or method of interventions and their learning, which are discussed further below.

### *Primary concerns*

A number of factors have been described as causing the high and persistent level of stress, anxiety and depression to parents of autistic individuals, compared to other parents. A generic classification is between child- (primary) and family- (secondary) focused concerns.

With regards to the first category, a study of 107 parents of children diagnosed with Autism Spectrum Disorders suggested that the child's difficulties causing 'parenting a child with ASD [to be] associated with elevated levels of anxiety, depression and stress' were: 'behavioral', which were deemed as most challenging, 'cognitive/learning difficulties', 'communicational skills' and 'lack of general independence' (Bitsika & Sharpley, 2004, p. 158). Parents reported low self-confidence in dealing with those difficulties, an inability that is making them feel 'angry and frustrated, inadequate, depressed, and isolated and lonely' (Bitsika & Sharpley, 2004, p. 159). Another quantitative study of 134 mothers of autistic children, clarified the relation between the two psychological factors, suggesting that parenting stress was a mediator between child behavior problems and self-efficacy (Rezendes & Scarpa, 2011).

Confirming the advantage to studying in depth individuals' subjective views, a more recent, qualitative study, which interviewed intensively 32 mothers of autistic children and nine professionals, both confirmed and further specified the nature of these concerns by differentiating between the following two 'sub-categories' of child-specific concerns: highly specific (sensory, motor, sleep, behavioral, affective mental health, digestive and nutritional) and more general and relating to activities and participation (social, communication, toileting, self-care, academic, personal relationships, community integration, vocational, independent living, autonomy, and self-advocacy) (Gentles, Nicholas, Jack, MacKibbon & Szatmari, 2018).

### *Secondary concerns*

Next to the concerns that are linked to the child's characteristics, both as an individual and with regards to their interaction with the others, such as their social life, stigma and victimization, literature review has identified as sources of concern the impact that the

stress itself has upon the parents' marital relationships, the financial burden, and the social capital (Bonis, 2016). Needless to say, when compared to parents of children with other neurodevelopmental or other disabilities, the 'burden' of parents of autistic children are found higher in this field too (Picardi et al. 2018), but this is not found to be related to demographic characteristics or other social qualities of the family, but rather on the characteristics of the child and the specific condition (Pastor-Cerezuela et al., 2020). In effect, in a systematic review of the relevant literature spanning from 2006-2019, the problems in spousal relationships have been identified consistently as linked to parental stress (Saccà, Cavallini & Cavallini, 2019). Gentles et al. (2018) described all those as 'secondary concerns', and highlighted that they stem from the 'primary' ones 'in several ways' (p. 8).

#### *Lack of information and guidance*

Both primary and secondary concerns are linked to a third source of stress related to both those categories: parents' need for information and pursuit of support. In a recent qualitative study where parents were interviewed, the limitation for resources, poor guidance from professionals, lack of awareness and stigma were found among their major concerns that generated significant levels of stress (Reddy, Fewster & Gurayah, 2019). Parents want to know "What is autism?", before and after the diagnosis, but also understand it and learn about the future of their child and the treatment (Girli, 2018). Yet there is endless information of all kinds out there, especially with the widespread use of the internet, and it is not always clear which information is right and they report feeling overwhelmed with the amount of available information about autism, which they feel they need to be informed about. This is experienced pre-diagnosis (Ceschamps et al., 2020), it is of course prevalent in the period of the 'diagnostic odyssey', as the process of diagnosis has been described due to the long and eventful ride it can be and highlighted the emotional, highlighting the social and financial burden of this process (Lappé et al, 2018), and continues after that. Parents have in fact described themselves the route following the establishment of diagnosis as a process of 'coming to understand their child has autism, going into high gear, and easing off' (Gentles, 2018, p. 1). Of course, apart from its emotional impact, the pursuit of information comes with a financial and time-consuming effect, both very precious

and often limited resource for people with such everyday demands (Mackintosh, Myers & Goin-Kochel, 2005).

Yet, despite the past focus on the negative psychological and social impact, things seem to shift towards a different area, especially when the parents are given voice and listened to attentively: for example, in a study parents valued the importance of the improvement of the child's daily activities more than the reduction of typical symptoms (MacConaghie et al., 2017), which had been the focus of research for many years. Similarly, in a recent mixed methods design of 134 parents of autistic children, the child, sibling and family's wellbeing and its relation to stress was deemed as a top priority, followed by the need for understanding, promoting awareness and providing support for anxiety at the school and the community (Clark & Adams, 2020).

#### Parents' quality of life

As was mentioned above, parents of children with ASD often experience increased levels of stress and depression and have to deal with additional roles for their children. They have to overcome the difficult process of getting a diagnosis, accepting what that means for their family, understanding autism, choosing the best possible intervention for their child and family, and become their child's constant advocate in a continuous struggle to provide them with the best possible opportunities. Apart from these challenges, however, they also experience additional strains in their everyday living situation. More specifically, they often have to deal with sleep deprivation, fatigue, increased caregiving responsibilities, and stigmatization from their immediate social network and community in general. They also have to support their children in dealing with many emotional and behavioral problems that add to the restrictions the whole family faces in terms of going on outings with friends, socializing with other families, going on vacations etc. Moreover, the demands of caring for a child with social and behavioral deficits and the lack of specialized child care leads to reduced opportunities to socialize and be involved in health promoting activities for parents themselves. All of the above strains mean that the quality of life at whole can be affected for parents of children with ASD, where research has been turning to in recent years.

In effect, more and more studies tend to look at the effect having a child with ASD can have on the quality of life of parents as a measure of a more comprehensive assessment of wellbeing. Quality of life (QoL) refers to an "individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns" (WHOQOL Group, 1998, p.11). It concerns a complex and detailed assessment of both positive and negative adaptation in many different domains of functioning that vary based on the scale used (e.g., general health, physical functioning, mental health, social functioning, environmental health).

Vasilopoulou and Nisbet (2016) provide a systematic review of studies measuring QoL of parents of children with ASD (aged up to 18) and its parental, child-related and contextual correlates. From the nine studies reviewed four studies found a broad impact of having a child with ASD on QoL, three found negative associations on the physical domain only, one on mental health only, and one on the environmental domain only. With regards to parental characteristics, mothers experienced lower QoL than fathers in most studies, whilst stress, coping style and parental self-efficacy were also identified as important factors influencing parental QoL. The most significant child related factor that had a negative influence on parents' QoL was the presence of behavioral difficulties. The child's age did not seem to have an effect whilst symptom severity was associated with QoL in only some studies. With respect to contextual factors the most important factor associated with QoL in the majority of studies was household income. Paid full or part time employment, as well as higher levels of social support was also associated with higher QoL in most studies, whereas support from services showed conflicting results. Marsack and Samuel (2017) also showed informal support to mediate the relationship between caregiver burden and QoL, whereas the same was not true for formal support.

This last result delineates the need to pay even more attention to the needs of the families in the development of services in order to enhance the acceptability and efficacy of interventions. This is even more important when dealing with families that have a child with ASD since many studies have shown that QoL is more detrimentally affected in comparison not only with regards to community samples but also in comparison with families that have a child with another disorder (Dey, et al., 2018; Eapen and Guan, 2016; Mugno et al., 2007). Lower levels of parental QoL can in turn have detrimental effects on their ability to support

the quality of life of their children and their family in general. Hoopen and colleagues (2020) showed that health-related QoL and care-related quality of life of primary caregivers and children were correlated, showing a possible interaction between the two. Parents mostly experienced problems in the relationship with the child and in combining care with daily activities, but despite negative effects the vast majority of parents reported deriving fulfillment from caring for their children.

In a similar review of relevant studies on QoL Eapen and Guan (2016) also report lower levels of QoL for parents of children with ASD, with maternal QoL being again the one that is most affected compared to paternal QoL. This could be explained due to the increased caregiving responsibilities mothers have in most families. Core ASD symptomatology and severity also provided conflicting results, whereas decreased social support for parents showed negative associations with QoL.

#### Parents' training needs

In the research of autism a discrepancy is often observed between the needs of autistic people and the available services (Nefdt, Koegel, Singer & Gerber, 2010; Suppo & Floyd, 2012). Implicating parents as interventionists, an idea that emerged more than four decades ago (Steiner, Koegel, Koegel & Ence, 2012) is a way to bridge this discrepancy. As was mentioned earlier, the parents' continuous presence and awareness of their child's characteristics and needs is considered as means to surpass the problems caused by the restricted time (in terms of number of sessions) and space (settings) that professionals are spending with the service user, also known as 'generalization' (Steiner et al., 2012; Harrop, 2015; Taylor, Hodapp, Burke, Waitz-Kudla & Rabideau, 2017; Prata, Lawson & Coelho, 2018). It has been found to lead to positive outcomes in many domains of autistic children's characteristics and needs (Estes et al., 2014).

However, unlike professionals, parents are often lacking the understandings and skills to respond to the specific characteristics and needs of their autistic children. Parents' training is an instrument that can address this lack (Sankey, Derguy, Clément, Ilg & Cappe, 2019).

The last two decades have seen an increase in the existing number and formats of training programs and research on the effectiveness of parents training. The overall observation is

that participation of parents in training programs seems to be impacting positively their children in making gains in language, communication and socialization, improving child-family interaction, reducing parental stress and increasing self-efficacy (Suppo & Floyd, 2012; Steiner et al., 2012; Preece & Trajkovski, 2017; Prata, Lawson & Coelho, 2018). This positive impact is not only viewed in conventional educational settings but also in those employing technology, which started with the use of VHS and DVD and expanded widely with the widespread use of the internet (Nefdt et al. 2010; Dai et al., 2018; Fisher et al., 2020). On the other hand, there have been observations of: no significant impact upon stress in particular types of training (psychoeducation) (Mukhtar, Hastjarjo, Kumara & Adiyanti, 2018); increases in stress after a certain time has passed from the training (Aly et al., 2013); persistence of low self-competence; and high stress linked to negative life events (Estes et al., 2014).

#### *Definition of training (vs. education)*

One of the main problems in this area, from which the conflicting findings that were noted earlier might arise, is the definition of training as such: it might be that the studies that come up with contradicting conclusions might not be describing the same thing. Indeed, 'parents' training' is not an area that is clear, unequivocal or undisputed. There is a variety in the terminology used in the literature (Dawson-Squibb & de Vries, 2019). Sometimes the terms 'education' and 'training' are used as contrasting, whereas, on other occasions, as interchangeable, causing much uncertainty and difficulty in reviewing the relevant literature (Cihon, Weinkauff, Oppenheim-Leaf, Taubman & Leaf, 2017; Preece & Trajkovski, 2017); the variety in 'formats, intensity, location, duration and target age groups' in parent training programs is adding to the complexity and need for clarification (Bearss, Burrell, Stewart & Scahill, 2015, p. 11).

In recent years there have been attempts to clarify what is meant by this term and how parents of autistic individuals can benefit most from a learning experience. Along with the gradual specification of what is meant by 'training', research has, unsurprisingly, seen a shift from the need to reduce symptomatic behaviors and decrease negative emotional impact to improving the autistic child's daily life and increasing the parents' quality of life, which was also noted earlier.

Bearss et al. (2015a) attempted to set the pace by discussing the need for clarification with regards to parents training, differentiating between, on the one hand, programs that offer parent-focused support and knowledge (mostly described under the term 'education') and, on the other, programs that provide parents with child-focused skills and techniques as a means for parent-mediated interventions (mostly described under the term 'training') aiming at behavioral changes in the child; the first category includes formats such as care coordination and psychoeducation, whereas the second includes primary and complementary parent-mediated interventions for core symptoms, maladaptive and disruptive behaviors. As was mentioned earlier, the second field has, in contrast to the first, been studied diachronically as related primarily to parental stress, since the social support parents receive, along with appropriate coping, which is often a part of training, is a mediator between the behaviors described as negative outcomes and parents' stress (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001). In effect, a study of 180 children led by the researcher suggesting this clear demarcation line, attempted a comparison between what they labelled as 'education' and 'training' programs upon their effect on the limitation of children's disruptive behavior (Bearss, Johnson, Smith, Lecavalier, Swiezy, Aman et al., 2015): the first program aimed at the provision of information and the second at the acquisition of skills for interventions that would decrease the disruptive behaviors according to ratings by parents as well as blinded clinicians. Both approaches led to the decrease of disruptive behaviors, yet a significant difference was found between the two, with 'training' versus 'education' deemed as more effective, yet without excluding the effectiveness of the latter and with the clinical significance of the improvement to remain 'unclear' (Bearss et al., 2015b, p. 1532).

In fact, it seems that this proposal upon a clear differentiation between 'education' and 'training' (Bearss et al., 2015a; 2015b) might not be feasible in real life and it has not been easy to follow by research and the clinic, since this was put forward (Sankey et al., 2019). It cannot but make one wonder how easy it is to limit an educational program to only theoretical understandings without teaching their application, or to teach skills and techniques without explaining the conceptual and theoretical and clinical background. For example, supporting parents in gaining a broader understanding of the principles behind the child-focused specific interventions, about behavioral management, can be more effective



as it can offer the flexibility that many training programs consisting of strict protocols are lacking (Cohin et al., 2017). It seems that successful educational programs, however they may be called, support parents in both developing understandings of their children's behaviours and managing them (Bonis et al., 2016). Yet what is the content of those programs regardless of the name we are using to call them?

### *Training needs*

The field of research in autism parents' needs, which has been growing in the past decade, had so far indicated a number of domains corresponding to the fields noted in the earlier section linked to parental stress and the decrease in their wellbeing. The area of challenging behaviors, which in the previous section was linked to high parental stress, seemed to be 'the most common goal of parent training' (Matson, Mahan & Matson, 2009, p. 871). Training in this area, specifically of the type of applied behavioral analysis was claimed to provide parents with skills for effective early interventions (Matson, Mahan & Matson, 2009). With regards to understandings, these domains have been identified as generic knowledge about this 'disability', 'how to interact' and how to 'advocate for their child' (Suppo & Floyd, 2012 p. 31). On the other hand, a more recent review of 27 relevant articles from the past decade noted that studies tended to emphasize on gains on the domain of social interaction rather than the management of restricted and repetitive behaviours described as the 'forgotten symptom' (Happor, 2015, p. 8). However, it is a question for investigation whether the 'goals' described earlier were set by taking into account first the needs of parents or professionals. The aims of those programs seem to be stemming from the educators or trainers' starting point, instead of the views, experiences and needs of the parents.

It is a fact that parents of autistic individuals have achieved so many in the past decades and they can contribute experts' understanding of autism and be involved in research and the developmental of clinical (Silverman & Brosco, 2007) and educational programs (Nefdt et al., 2010). However, although they are the most significant stakeholders in the matter of autism, current research on autism is not aligned with their voices, needs and views. It has been observed that in the majority of the studies of the past decade, the format of training is designed beforehand, based on the expertise of professionals, instead of that of the parents. The need to ask for the parents' views and contribution beforehand is not simply

because they are the primary stakeholders, but also because they are a 'a valuable source of information and localized expertise, not only about their own child, but [...] autism in general' (Silverman & Brosco, 2007, p. 396).

It seems that this ground has started being covered only very recently. In fact, research is picking up on the significance of involving autism parents in setting the priorities and need for autistic individuals and their families (Clark & Adams, 2020), and it is, among the priorities of the present study to continue on this pathway, giving voice to the stakeholders and service users themselves.

An example on this direction was given by an innovative Erasmus+ funded program, which investigated quantitatively 148 parents' training needs in two Balkan and one Mediterranean country (Croatia, North Macedonia [then FYR Macedonia] and Cyprus) (Preece, Symeou, Stošić, Troshanska, Mavrou, Theodorou & Škrinjar, 2017). Despite the variation between the countries, five domains were identified by parents as priorities for training, towards which they were overwhelmingly positive (90%): strategies for enhancing their child's communication, facilitating its interaction with other children, sensory integration and development, general information on behavioral management techniques and identifying or developing socializing opportunities (Preece et al., 2017). It is noteworthy that the management of behavior, which in the past has been the main or only component of parent training programs designed by professionals, is not absent, but only a part of the overall needs parents themselves identify. It would be very useful to investigate and specify further those findings also from a qualitative perspective to see what lies behind those domains and whether their address in a new training program could impact positively parents and autistic individuals, avoiding the relapses documented in the past.

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## **INTEGRATIVE PARENTS' AUTISM TRAINING**

### **FOCUS GROUPS' GLOBAL REPORT**

#### **1. INTRODUCTION & METHODOLOGY**

The focus groups in the four countries of IPAT took place between December 2020 and March 2021. More specifically, the respective dates were:

- Greece: 19<sup>th</sup> December 2020
- Spain: 18<sup>th</sup> February 2021
- Turkey: 3<sup>rd</sup> March 2021
- Italy: 20<sup>th</sup> March 2021

The duration of the focus group lasted between 2-3 hours. More specifically:

- Turkey & Spain: 2 hours
- Greece & Italy: 3 hours

On three occasions, the focus group (Greece, Spain, Italy) took place online due to the restrictions of the Covid-19 pandemic, whereas in one country (Turkey) it was held in person.

For the online versions, the three partners made use of Google Meet for running the focus group, and other software for recording and transcribing it (Greece: Movavi; Italy: OBS; Spain: Apple and WhatsApp). Google Meets was chosen because it does not require installing any particular software or platform on the computer. On all three occasions trials with the participants were conducted prior to the actual date and time of the focus group.

Participants were recruited either indirectly, through third parties not linked to the partner organization (Greece, Turkey), or directly through the services of the partner organizations (Spain, Italy), yet on all four occasions the participants did not know in person the focus group moderators.

On all four occasions, the participants came from both the cities where the partners are based (Athens, Catania, Burgos, Gaziantep) and from other regions of the country.

All partners aimed at covering a wide range of age and typology of autism.

The participants were sent an original briefing form, then an informed consent form to fill and return signed via e-mail, and, finally, a debriefing form, after the end of the focus group.

On two occasions (Greece, Spain) the focus group was coordinated by one moderator and one observer, both mental health professionals with experience from autism, whereas on the other two occasions (Italy, Turkey) there were one moderator and two observers.

The main moderators set the questions, moderated the discussion and summed up each topic and the whole discussion. The observers held the role of welcoming the participants, took care of the electronic equipment and the recording of the session and kept notes about the extra-linguistic behavior as well as the interactions among participants.

The total sample consisted of 23 participants (there were two last minute drop-outs, in the case of Greece and Italy). Out of the 23 participants, 7 (30%) were fathers and 16 (70%) were mothers of autistic individuals. In addition, 18 (78%) were parents of autistic boys/men and 5 parents of autistic girls/women (22%). More specifically:

- Greece: 5 participants: 4 mothers, 1 father; all of boys/men
- Italy: 5 participants: 3 mothers, 2 fathers; four of boys/men, one of girl/woman
- Spain: 7 participants: 4 mothers, 3 fathers; five of boys/men, two of girls/women
- Turkey: 6 participants: 5 mothers, 1 father; four of boys/men, two of girls/women



Participants were asked questions about parents' expectations from clinical and educational services, about their needs and the scope, content and instruments of a training program they would attend.

The focus group guide used in the first focus group (Greece), was translated in English, shared and discussed with the other three partners on the Kick Off Meeting of Athens on 28<sup>th</sup>-29<sup>th</sup> January. Based on the experience of the first meeting and the discussions that followed, there were alterations, both on the content and on the way that the questions were posed to the participants.

The focus group guides were re-translated from English to each partner country's language (Spanish, Italian, Turkish). With regards to the actual questions, one basic question was added to the original focus group guide that had to do with the role the participants hold with regards to their autistic child. There were other minor changes with regards to each country's specific particularities, involving their language, after work within the partner organizations (Turkey).

With regards to the way the questions were conveyed, on one occasion (Spain) the participants were sent the questions one day before so that they could familiarize themselves with them. On another occasion (Italy) the moderator and observer shared the questions with the parents through the share screen application, so that they could see them.

All participants contributed to the conversation, although some spoke more than others, as usually happens in this kind of meetings. There was not a pattern suggested for the rotation of speech, which was agreed by everyone in a spontaneous way, but all participants were asked from the moderator to participate.

## **2. RESULTS**

1. At a first stage, participants were asked about the shared their role with regards to their autistic child. They agreed that their role in the care and training of their children is critical as those who know their children best and fundamental as guarantors and defenders of their rights, in a constant work of communication,

coordination and mediation with other professionals, and at the same time collaborating in everything that they need. They are the ones who take care of the family on a global level in its entirety and peculiarity. They feel they must be empathetic, accessible, and generate trust like professionals. For many participants, there is a clear demarcation line between the role of parent and therapist, which they do not assume or want to assume, although there were occasions where this is not equally clear.

2. One of the main points of agreement among participants regarding the scope of a training program was the need to understand what autism is, both as a target, but also with regards to its objectives and instruments to achieve that. Participants stressed the lack of detailed information about autism, particularly when the process of diagnosis and becoming aware of what autism is started for them: what is autism, what it entails and what kind of behaviours should they expect to see in their child? How should they cope with them? What is the diagnostic process, the educational opportunities and lifelong reflections of autism? All parents mentioned that any training program should include information about the different age groups and levels of functionality. Also, about the child's capacity for independence and autonomy was also recurrent. Participants stressed the importance of acquiring methodologies and strategies in a training program that are useful for improving those aspects of the life of a child with ASD.
3. The support families have received from professionals was a critical issue and the subject of the professionals they have met and their experiences from them, mostly negative, emerged on many occasions. Many participants have had a hard time coming across experts who, on their opinion, did not have the necessary competence. They therefore agreed on the need to identify professionals who are able to transfer their skills and useful strategies in order to enter into greater contact, empathy and relationship with their child with ASD, give them support in critical moments and follow the family in long-term goals. As part of a training program, this could involve information about the therapist's training.

4. Participants mentioned that the psychological support of families with children with ASD could be among the aims of a training program. They did not forget to mention here the aspect of the autistic child's siblings. Problems that are impacting the entire family's wellbeing were psychological burn out, social isolation, a feeling of not being understood by the others, as well as issues of domestic life. Some techniques that families said they would benefit from training in this direction are anxiety management and self-control of emotions and frustrations, social skills, personal autonomy, and relaxation techniques, both for them and their children.
5. Parents emphasized how important the aspect of socialization, the social life of the child and family and social inclusion of their child is. Stigmatization and bullying were mentioned by many families as a negative factors affecting the child and family's wellbeing, hence parents stressed the significance of cooperation with the educational background and the whole community to tackle this issue. Everyone agreed that the subject of the child's social skills, socialization and social inclusion is very significant to exist in a training.
6. The subject of the parent's interaction with the child and the capacity to spend quality time with their child was also raised as a very important issue and a subject for training. The importance of alternative ways for a parent to communicate with their child in order to achieve that was thus also stressed.
7. Another particular need for training that were raised that should be included in a training program was sexuality, awareness of sexual needs and the management of the sexual drive.
8. Another need for training that should be included in a training program for the parents is that of the rights and legal issues of the child and family. Participants stressed the need to become aware of the rights and guarantees at national level of their children, since the knowledge of this issue would allow them, barely trained in this regard, not to suffer injustice and abuse from institutions, as well as obtaining

the resources and subsidies that they are entitled to. They further mentioned the importance of detailed information about the necessary legal procedures and documents, and institutions served and the matter of legal incapacity for those whose children have a lower level of functioning. The knowledge of the rights would become for them a foundation of protection and guarantee of dignity.

9. The mode of learning that parents agreed upon was that it should not be too theoretical, technical or specific, but primarily practical, in everyday language and experiential. They mentioned as suggestions: the use of many examples, practical solutions, role playing, direct observation, videos, demonstration, role modeling, learning by doing, a booklet, participation in support and discussion groups for the practical aspects of child management, even with parents having children from different ages and levels of functionality. Training should use specific and concrete experiences of the participants for their programs and not generalizable experiences typical of manuals; this would help the parent individualize the case of their child. Participants added the need for practical solutions that would help them attend the training, such as time, specific hours, access to the training setting and even child care (someone taking care of the children while they attend the training); all these may be detrimental factors from attending a seminar, as well as the need for both parents of the child to attend any possible training.

### **3. CHALLENGES ENCOUNTERED**

- *Participants*

The original number of participants in each focus group was six, aiming at a total sample of 24 participants (4 focus groups x 6 participants). However, there was a last-minute drop out on two occasions (Greece, Italy), ending up with five participants in those two focus groups. There were no drop-outs in the focus groups of Turkey and Spain. The focus group of Spain had in fact raised the number of participants to seven. The total number of participants was 23, instead of the originally planned 24.

Another challenge was the representation of fathers in the groups, who are also under-represented in the bibliography in general, and were not easy to find. However, the presence of at least one father in each group was achieved, with two focus groups (Greece, Turkey) having one, one focus group (Italy) having two and one focus group (Spain) having three. The total number of fathers was, in the end, smaller than that of mothers (7 vs. 16), but the percentage (30%) is still much greater than in existing research bibliography.

Another challenge with regards to the participants was the age, level of functionality and gender of children. A range of ages, levels of functionality and gender was achieved, although the representation of girls being smaller to those of boys, as happens also in the existing bibliography and epidemiological data. The final characteristics of children of the participants were:

Age: 11 young children (under 12 years old) (48%), eight adolescents (13-17 years old) (35%), four adults (17%)

Level of functionality: seven low (30%), 11 middle (48%), eight higher-functioning autism (Including Asperger's syndrome) (22%)

Gender: 18 boys/men (78%), five girls/women (22%)

- *Running the focus group*

The case of the online platform was followed due to the Covid-19 pandemic restrictions (lockdown) in three focus groups (Greece, Spain, Italy), whereas one focus group (Turkey) took place in person, with all the necessary precautions and measurements because of the Covid-19 situation.

With regards to the online version, in order to avoid difficulties people connecting to the platform, trials were conducted beforehand with each participant, which were very useful and avoided technical problems. On some occasions, there were some very minor, temporary issues that were resolved immediately and did not affect the smooth flow of the focus group.

The matter of the use of (open/closed) microphones and the activity of raising one's hand to speak was not a problem, since participants familiarized themselves very quickly with it.

An order of participants speaking was created and helped every one speak.

On some occasions, participants introducing themselves took more time than expected, but this was tackled with an amendment of the focus group introduction and guide and with allowing more time for the overall session, and in the end did not impact negatively the final outcome.

On some occasions, it was not easy for some participants to stick to speaking about the questions asked. This was tackled by different ways, such as sending the questions beforehand to them, so that they are prepared (Spain), showing the questions with the share screen activity on the online platform (Italy) or intervening in a more direct way during the session, to specify and/or clarify things (Greece, Turkey, Italy).

- *Focus group guide (questions)*

The original focus group guide (questions) was generated by the first partner running a focus group (Greece: Child and Adolescent's Center) based on bibliography and views shared with professionals and parents of autistic individuals. It consisted initially of five questions. In the Kick Off Meeting of Athens, that was held online, on 28<sup>th</sup>-29<sup>th</sup> January 2021, the pros and cons of the focus group guide (questions) was discussed with the other three partners and amendments were suggested and adopted.

One partner (Spain) suggested the addition of one question about the role of the parents with regards to the training of their children, which was then adopted by the remaining two partners (Turkey, Italy) that had not run their focus groups yet.

One partner (Turkey) did successive meetings to adjust the questions to the particularities of their country.

#### **4. COUNTRY SPECIFIC PARTICULARITIES (AS RAISED BY PARTICIPANTS)**

In all countries country-specific particularities were raised, described in the present section, specifically for each country:

- *Greece*

One significant country specific characteristic in Greece that emerged in the focus group is the status and organization of clinical services available for autistic individuals. In Greece, the state services occupy a very small part of the area of service provision (diagnosis and treatment) for autism. The greatest part of the services available to the autistic individual and families is private and non-profit organizations.

Another challenge was the obscurity about this state and organization of services. This makes difficult the journey of the autistic individual and their family, which is left with very few information, in order to decide when, where and whom to address in order to reserve services; from diagnosis to treatment and other support, like social or legal.

Moreover, the available services, less statutory and more private and non-profit, are based in Athens, the capital, where resides half of the country's population. There are very few services in big cities or even the rural areas, and as a result the limited availability and information make it harder for the autistic person and family to decide what type of support to request and from where to request it.

Another country-specific characteristic that was discussed was the limited amount of specialized services concerning matters like sexuality. One participant referred to the existence of relevant services or practitioners abroad, something that in our country, both in terms of knowledge and practice, is very limited. This is also discussed below, as it is linked also to cultural matters.

- *Turkey*

In terms of diagnosis and educational guidance services, the parents of autistic children can follow a very well-organized procedure. The system in Turkey can be easily followed by the parents. In Turkey, public and private educational services are available for autistic individuals. However, the educational facilities are very limited in public and private educational institutions. Specifically in Gaziantep, Gaziantep Municipality Center for the Disabled is regarded by the parents as a unique place to obtain professional help for their children.

- *Italy*

One very important country specific aspect which emerged from the focus group, emphasized the feeling of disorientation, misinformation and discouragement following the diagnosis of ASD of one's child and the bureaucratic waiting times (very long in Italy). The

families, for these reasons, don't feel supported and directed about the right of their children: concessions, subsidies, and insertion into the school world. In order to fill this feeling of frustration and loneliness very often the parents of children with ASD turn to private services dislocated in the surroundings, or in the region they belong.

During the focus group, one of the participants shared his decision to start home rehabilitation therapy courses for the child with ADS instead of the private centres. Having a child with a diagnosis of autism is a painful experience for families. International research reviews show parents of children with ASD experience high levels of chronic stress and feel responsible for the condition of the child, experiencing guilt, anxiety, anger and depression. Indeed the psychological support for parents and siblings, turned out to be an important topic during the focus group.

- *Spain*

In Spain, particularly in the region of Burgos, there are public and private services available for autistic individuals, in health, education and social fields. Coordination and networking between them is more and more strong and fruitful every day, in a back and forth way.

Families can receive diagnosis in public health systems or in private and non-profit organizations (Autism Burgos); compulsory education, until sixteen, is covered by ordinary school, although there is a specific school for people with autism too, both modalities into the public system.

Autism Burgos is the only private and non-profit organization dedicated to people with autism in Burgos and region, including the main headquarters in Burgos and three delegations in three small towns of the region, Aranda de Duero, Miranda de Ebro and Medina de Pomar.

Parents also report the distant and unsympathetic attitude of some healthcare professionals, specially when they receive the diagnosis: they don't feel heard, it looks like professionals talk about autism in general, not about their child in particular, and use technical and scientific words difficult to understand. In other cases, professionals aren't specialist in autism, they don't have enough practical knowledge to understand what happens to their child in particular.



## 5. POTENTIAL CULTURAL ISSUES RAISED

As with the country-specific particularities, cultural issues were raised on all occasions, described in the present section, specifically for each country:

- *Greece*

One cultural issue in Greece that interfered with the actual running of the focus group was the mode of addressing others and conversing. The question was if question participants and moderators would address each other in the singular or plural number. When you meet someone in the Greek culture for the first time, you do not address them in the singular or first name directly. However, for matters of confidentiality and methodology, it was decided from the beginning to ask people to address each other in the singular and first name. Yet, as this is not something usual in our culture, it made moderators feel uncomfortable (the participants themselves did not express any particular view about this. Both moderators and participants used the compromise “Mr. (first name)”, which is not proper or usual.

The matter of sexuality, which was also discussed above in terms of country-specific particularities, is not something that is not linked to cultural matters. The issue was raised by more than one participant, also comparing to the state of services available here with other countries. However, the matter was still raised in a very timid way, making it obvious that participants felt uncomfortable in setting it. For example, the matter of masturbation was only implied and described indirectly, without calling it by its name, or even a synonym, of which there are available names that are acceptable in the Greek language and culture (e.g. self-pleasing or aunanism).

Another cultural matter, which is found in other countries too was the amount and percentage of male parents who are interested and involved in the caring of their autistic children. We had one father as part of the group, whereas one other father had expressed an interest to take part but was not invited for matters of methodology. Although this is a very frequent research finding, it is a question whether in other countries the percentage is the same or not. This is linked to another matter that was observed in the focus group, that of the presence of single -parent families, of which there were two out of originally six participants, that is, one third. In both cases participants shared that the fathers of the

children left the family and that in some occasions they are involved in the caring for the child, whereas in others not.

- *Turkey*

In the Turkish culture, talking about your child's daily life difficulties is a bit difficult since parents emotionally feel uncomfortable. For this reason, the participants in this project were somehow uneasy while talking about their children's difficulties related to autism. Another cultural issue was about talking about the negative attitudes showed by the family members of the participants. Therefore, the participants did not prefer giving details about the problems they live with family members. Lastly, the Islamic religious principles tell the Turkish Muslim individuals to be thankful to God about their current situation, whether it is favourable or not. Our participants were all thankful to God about their own and children's current situation. This fact led the participants not to complain about their own and children's current situation.

- *Italy*

In Italy, the caregivers of people with disabilities, unlike other European countries, have no legal recognition and no type of legal protection and social recognition. Family caregivers are those who take care of people who cannot be self-sufficient- due to the important disabilities, at home, in a free, continuous and quantitatively significant way (for many hours a day and for many years). The roots of this theme could be traced to a completely cultural question. Often families with people with ASD, live in a family environment, based on the family approach to assistance. What follows next, indeed, is an approach based solely on the care and assistance of the other and the inability and /or impossibility of thinking and self-determining themselves as "those who can also do something for themselves". So parents of people with ASD, often live in a reality in which the sense of duty is excessive, and this can lead to neglecting one's needs as a single parent and /or parental couple, causing the fear of being inadequate in the eyes of others in case of personal needs. In the focus group, for these reasons, the participants encountered difficulties in being able to think of themselves as recipients of training to help people with ASD.

Although, the family and the sense of belonging to it is a very important and particularly felt topic in Italian culture. From the focus group, it emerged that it would be determined for

the participants to extend the training in ASD to siblings, grandparents, cousins and uncles in order to facilitate their understanding of the relationship with the child with ASD.

During the focus group, just one participant (female) claimed she manages and supports almost exclusively the child with ASD and she does not receive help from their spouse. For the other participants, it seemed that both spouses have different roles and together collaborate for managing the child with ASD. Two of the five participants were in fact fathers of children diagnosed with ADS and described themselves as actively interested in the management, participation and care in everyday life and management of difficulties with their children.

- *Spain*

One cultural issue we usually find in education topics is the amount and percentage of male parents who are interested and involved in the caring of their children. Fortunately, this did not happen in this case, and we counted with three parents and four mothers in the group, showing similar knowledge and implication in the matter.

The matter of sexuality was openly discussed, showing lack of cultural prejudices. The topic that really made some participants feel uncomfortable was the legal incapacity, as they reported having had an unpleasant experience when they were advised to incapacitate their son, feeling like acting against their own children, as “bad fathers”. They recognized the need for advice and support in this kind of topic. Fortunately, one of the mothers was willing to offer her collaboration and support.

## **6. LESSONS LEARNT**

- *Participants*

The first focus group (Greece) ended up with a smaller variety of ages and levels of functionality of participants' children than aimed for. This was communicated immediately after the running of the focus group to the other partners, in order to take it into consideration for their recruitment of sample. The other partners (Spain, Turkey, Italy) managed to have a wider range of ages and levels of functionality, ending up at the total sample having a wider spectrum of parents of autistic children. Despite the disadvantages that may lay in having parents of children with very different profiles, characteristics and

needs, it was concluded that this gave out rich and useful data for the content and structure of the module, more than it would have probably been, should the sample was restricted to parents of children of certain age group and level of functionality. This is something to consider for the participants to the actual training of the module that will take place for the Intellectual Outcome 2.

The same happens with the under-representation of fathers vs. mothers and autistic girls vs. boys in research and bibliography, which we tried to address in a similar pattern: it was something that occurred in the first focus group (Greece; one father, no girls), so the experience led immediately to an encouragement to the other three focus groups that would take place after at least two months (Spain, Turkey, Italy) to try to address this issue. We ended up, in the final sample, of fathers being 30% of the participants and parents of autistic girls 14%.

Concerning the number of participants in each focus group, we discussed among partners the question of a replacement standing by, in case one of the original six participants did not show up, so that the original goal set was met. This emerged after first drop-out in the first focus group (Greece), which had decided to not have a replacement, in order to avoid frustration to that person, should they were not called in. Yet partners agreed to not have one. As a result, there was another drop-out (Italy), whereas there were no drop-outs in the remaining two countries (Spain, Turkey). In fact, on one occasion (Spain), a parent's wish to participate in the focus group despite the fact that the total number of six had been met, was addressed and hence the final number was seven. In none of the three occasions (two drop-outs, one extra participant) did the variation in the final number of participants affected the running of the focus group.

- *Focus group meeting*

Concerning the running of the focus group online (Greece, Italy, Spain), the trial of the online platform beforehand (either one day before, or on the same day, earlier), helped a lot to resolve technical issues that could have appeared on the day of the meeting. Only minor issues happened, which did not affect massively the process.

As far as the in person running of focus groups is concerned (Turkey), researchers report that having the opportunity to meet face to face the participants, increased the chances to obtain more detailed and focused data from them, avoiding the disadvantages of online meeting, which had been chosen in the other three countries due to the restrictions of the Covid-19 pandemic.

The duration of the focus group varied, from two to three hours, which did not seem to affect the final outcome. On the first occasion (two hours; Spain, Turkey), a break was not required, whereas on the second (three hours; Greece, Italy) it was deemed very useful by researchers.

The moderation by one main moderator and support by observer(s) was a model that worked very well. No issues were reported. The number (one or two) of second moderators (observers) did not seem to have any significant effect on the final outcome.

## **7. SUGGESTIONS FOR THE FORMULATION OF THE IPAT MODULE (TOPICS)**

### **1. What is autism?**

- Definition
- Biological background (genetic, epigenetic, risk factors)
- Clinical characteristics and manifestations (social communication and interaction, repetitive behaviors, comorbidities, sensory integration deficits, functionality groups)
- Social communication, interaction and social skills of the child
- Diagnostic criteria and diagnostic tools and procedures
- Epidemiological characteristics (frequency, gender distribution, gender-specific characteristics)
- Prevention

### **2. Therapeutic approach**

- Assessment
- Therapeutic interventions
- Scientific and inter-sectoral collaboration
- Objectives and quality of life

- Skills for everyday life
3. Legal and ethical issues and rights
- Basic rights
  - Legal support
  - Benefits and alleviations (subsidies and scholarships)
  - Professional ethics
  - Professional training
  - Advocacy
  - Legal incapacity
4. Lived experience of the family
- Psychological distress
  - Bereavement
  - Acceptance
  - Role of the family
  - Fathers and mothers
  - Siblings
  - Extended family
  - Sources and means of support for the family
  - Issues of support provided by professionals
5. Parent's interaction with the child
- Creative time and wellbeing
  - Modalities to structure an efficient and enjoyed interaction with the child
  - Tools for parent's communicating with the child
6. Social inclusion and autonomy
- Prevention and management of bullying and stigma
  - Community education
  - Inter-professional and inter-sectoral collaboration
  - Employment and work
  - Autonomous, semi-autonomous and assisted living
  - Leisure time

## 7. Sexuality

- Puberty
  - Personal relations
  - Expression and satisfaction of sexuality as a right
- Following the suggestions of the participants a) all the topics suggested above should be considered as age-, developmental stage- and functionality-specific and b) active interaction among parents during the training should be encouraged.

## 8. APPENDIX

### 1. THEMATIC ANALYSIS RESULTS

#### 1) Understanding autism

- "definition and explanation of what autism is?"
- "definition as neuro-developmental disorder"
- "understanding what autism is and what it means helps set realistic goals"
- "understanding the autistic child's viewpoint"
- "understanding the different needs and expressions"
- "diversity inside the whole spectrum in core symptoms"
- "interventions in the natural context"
- "understanding and development of the disorder"
- "disinformation/ lack of detailed information about autism"
- "previously incorrect information"
- "lack of detailed information about definition and explanations of autism"
- "importance of timely assessment/ timely diagnosis/ understanding first what is not going well"

#### 2) Psychological distress and impact on the family

- "need of psychological support/ access to psychological support"
- "siblings"
- "difficulty accepting that the child has autism"
- "not being understood by the others"
- "feeling of anxiety in social environment"
- "social isolation of the parents/ family"
- "importance of parents' support by professionals"
- "seeking therapists' help and support"
- "reliance on professionals"
- "feeling misunderstood by professionals"
- "support in making decision"
- "anxiety about the child's acquisition of future life skills"

“anxiety about the child’s life in the absence of a parent/ after us”  
“mental exhaustion”  
“exhaustion/ tiredness”  
“guilt of parent”  
“loneliness and helplessness”  
“frustration”  
“considering the price of sin (interpreted as punishment for the family)”  
“fear of having a new child”  
“shock for the family”  
“conflict between spouses due to greater burden of care on the mother”  
“psychological burden, frustration, demands from the parents to be co-therapists not always realistic”  
“resilience”  
“need of a miracle”  
“idealized thoughts by parents”  
“siblings”  
“brothers/ negligence of and from the brothers”  
“grandparents, uncles, cousins/ “conflict with relatives (because they do not feel understood”  
“importance of help from family members”  
“inability to establish communication between children with autism and their siblings/ social life with siblings”  
“improving motor skills”  
“taking charge of the family at 360 degrees”  
“conducting and maintaining the social life within the family”

### **3) Social communication, interaction and skills**

“importance of the lacks in the social element and interconnection”  
“importance of socialization/ being with other people”  
“the school as a social environment vs. attendance/ cognitive level”  
“importance of being with other people”  
“avoidance of special education service”  
“social element”  
“social conditions, social interaction”  
“management of the child’s social life”  
“Impact on the whole family”  
“insufficiency of socialization areas”

### **4) Understanding and managing specific behaviors**

“improvement of behavior”  
“child’s tolerance of frustration”  
“play – interaction, stereotypies, matters of sensory integration = decoding and understanding behaviors plus ways for interchange and interaction”  
“hand flapping”  
“body rocking”  
“toe walking”



“spinning objects”  
“sniffing, immediate and delayed echolalia”  
“running objects across one’s peripheral vision”  
“management of obsessions and stereotypies/ methods to manage the stereotypical behavior of the child/ problem behavior management strategies”  
“self-regulation strategies to parents”  
“characteristics and behaviors that are challenging”  
“obsessions”  
“understanding and managing sensory issues”  
“how to handle with limits respecting idiosyncrasy from autism”  
“limits and rules”

**5) Child and parent interaction**

“nonverbal communication – achievement”  
“creative time – play/ need to know how to play with the child”  
“sharing time, feeling”  
“training on the parent-child interaction”  
“well being”  
“(inability to establish) communication – interaction with the child”  
“need to enter into empathic and communicative contact with the child”  
“joy- enjoyment from interaction with the child”  
“interaction with the child”  
“need to know how to empathize”  
“tools for the parent’s communication with the child/ understanding needs and requests”  
“global strategies to improve weakness and talents”  
“ways of learning and interacting with the autistic child (video, images)”  
“tools for visualization + digital”

**6) Social inclusion and autonomy**

“importance of lacks in social element and interconnection”  
“bullying”  
“employment, work”  
“social inclusion”  
“autonomy”  
“basic autonomies/ domestic autonomies”  
“independence”  
“teaching self-care skills”  
“social inclusion vs. educational section”  
“work or employment in adult life and generally support, framing/ job placement”  
“stigmatization of autistic individuals as ‘idiot’”  
“prejudiced individuals in society”  
“Not being accepted by the parents of other children”  
“co-management of stigmatization and pursuit of support in the broader family/ how to explain and get awareness to the whole family, need support/ educate the extended family”  
“what will happen when parents die or can no longer manage/ after us”  
“behaviors and social inclusion”

“community education”  
“show of excessive compassion for the child with autism (in a way that will disturb the child)”  
“education in every setting where the child is introduced”  
“smooth social-educational route”  
“information at school, creation of an accepting environment necessary for social inclusion/ need for cooperation between specialists and school”  
“daily life skills (going to the market, shaving, hairdresser, opening the door for outsiders)”

#### **7) Sexuality**

“sexuality”  
“management of sexual drive”  
“sexuality education (awareness of sexual needs)”  
“sex education”  
“in relation to sexuality, specific attitude and viewpoint”  
“sexual subject”  
“rights, the expression and satisfaction of sexuality as a right”

#### **8) Rights, legal and institutional issues**

“awareness of basic rights and specific legal precautions – alleviations – there must be systematic information”  
“knowledge of the rights provided by the law at national level”  
“information about the institutions served/ disinformation of the public administration”  
“differences between resources in rural environment vs capitals”  
“legal support”  
“importance of ‘legal elements’ and rights”  
“information about the necessary legal procedures and documents”  
“rights/ legal rights of individuals with autism”  
“rights and subsidies”  
“training and ethics of professionals/ public administration”  
“need for control of specialists / experts not have the necessary competence”  
“access to experts when needed”

#### **9) Structure of training according to age and levels of functionality**


“importance of lower functionality” / “forgotten children”  
“adulthood/ the future”  
“classification/ differentiation according to age”  
“life periods”  
“significance of continuous training”  
“continuous training and remaining needs/ not everything solved with one training /aiming at age/ aged-focus training”  
“transmission of ‘know-how’ between parents of children of different ages”  
“importance of children of different ages”

#### **10) Methodology of training and practicalities**

“apart from training, personalized guidance”

- "visualization"
- "demonstration, role modelling, learning by doing, booklet"
- "simple and understandable language"
- "importance of both parents attending"
- "support parents training groups"
- "importance of examples and application"
- "skills for everyday life"
- "life-long learning trainings focusing in next steps"
- "specific training skills for parents based in individualized plans"
- "online learning"
- "experiential character of seminar"
- "care of children during the seminar to facilitate attendance/ providing care for the child"
- "providing access to the training setting"
- "facilitation of attendance"
- "setting the appropriate hours"
- "practical support to families"
- "audio-visual material"
- "practical application of what is developed"
- "assessment of parents' need before training"
- "active participation in the sense of parents expressing themselves and exchanging views"

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