

Literature Review

Integrative Parents' Autism Training

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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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