

Focus Groups' Global Report

Integrative Parents' Autism Training
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INTEGRATIVE PARENTS' AUTISM TRAINING FOCUS GROUPS' GLOBAL REPORT

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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: 19th December 2020
- Spain: 18th February 2021
- Turkey: 3rd March 2021
- Italy: 20th 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 28th-29th 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 trainign 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 streed 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 was 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 28th-29th 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 them understanding or 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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