



Country Specific Reports

Integrative Parents' Autism Training

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1. INTRODUCTION

The IPAT training activity was delivered in Greece from 12/03 until 11/06, consisting of 8 three hours-long sessions that took place on Saturdays 11.00am-14.00pm in Greek language. Over this period of five months, the participating parents received knowledge and guidance about key issues related to autism, including new perspectives on the understanding of autism, available support and therapeutic services for children with ASD, the role of family members in the care of children with ASD, developmental issues and sexuality, the rights of individuals with autism, among other topics directly relevant to parental needs. Participants were also able to engage in activities that enabled them to reflect on these issues, identify and acknowledge their own needs, by interacting with other parents and sharing valuable experiences and relevant information.

The aim of the IPAT training activity was to deliver a psychoeducational programme for parents of individuals with autism and consequently design a digital self-learning tool, based on previous research and the review of literature on parental needs. Psychoeducation is a specialised form of education aimed at helping to learn and creating awareness about a range of emotional and behavioural difficulties, their effects and strategies to deal with them. Thus, the focus of psychoeducation is the provision of practical help. In this respect, the IPAT training activity was structured and delivered in a way that balances academic content and accessible, applicable, skill-building knowledge in order to bring about a positive impact on stress level and perceived quality of life.

Participants were recruited by creating an invitation poster that described in detail the requirements for participating to the IPAT training activity. The invitation was distributed to

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parents of children with autism through professionals and organizations associated with the Child and Adolescent's Centre (CAC), such as regional and nation-wide institutions and day centres for autism, family associations, private practitioners and professionals and schools. Participants were not directly linked to the CAC and met two essential selection criteria: a) they had no prior experience of attending a psychoeducation programme in autism and b) that they actively commit to the IPAT training activity until its completion. 21 one parents were recruited and signed a confidentiality form via e-mail before the onset of the training activity. There were no constraints as to the age of the child with autism and the level of their functionality.

All IPAT sessions were delivered and coordinated by two moderators, both mental health professionals with work experience in the field of autism, who were recruited after responding to a job advertisement created for this purpose and after attending an interview. Each IPAT training session took place via Google Meets. Google Meets was chosen because it does not require installing any particular software or platform on the computer; you only click on a link. The link was sent to all participants a few days before each scheduled meeting. Each meeting followed a fixed structure, consisting of four 15' lectures, 10' for questions, 10' coffee break, 45-60' for reflection and experiential activities. Overall, the duration of each meeting was scheduled for three hours.

2. STRENGTHS AND WEAKNESSES OF THE IPAT TRAINING ACTIVITY

Strengths

- The IPAT training activity as a psychoeducational programme attracted the interest of large number of parents. Eventually, 21 parents enrolled for the programme and 20 of them attended the first meeting.
- The selected delivery method was online via Google meets. This enabled participants from different locations in Greece to join the IPAT training activity. No major technical issues occurred and all participants were able to easily use Google meets and make effective use of break out rooms in the experiential activities.

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- Participants demonstrated strong engagement in the discussions and the interactive activities with other parents.
- The IPAT training activity supported parents by enabling them to develop knowledge and skills in essential areas related to care and understanding of autism.
- The content of the IPAT training activity consisted of PowerPoint presentations, accompanied by interactive activities which were designed for each meeting and complemented well the main topic covered by the presentations.
- The IPAT training activity allowed participants to share valuable information and experiences about raising a child with autism (e.g. their experiences about dealing with everyday issues, information about available services, governmental schemes etc.) and this enhanced the bonds created with other participants.
- The content of the presentations and the activities was consistent and relative to participants' experience and illustrative examples were used that fleshed out theoretical ideas.
- There was excellent collaboration between participants and moderators and among moderators themselves.
- Participation in the interactive activities was particularly useful as parents were able to reflect on several issues and develop insights about how they relate to themselves, their child and family and their social context in general. Moreover, emotive material emerged that enhanced the closeness between the group members.

Weaknesses

- One main weakness of the training, identified at an early stage, was the duration of the presentations which went longer than initially planned. Especially, in the first two meetings, the lectures went over the 15' allocated time and eventually this caused fatigue to the participants who felt they were overloaded with information.
- The content for some of the presentations included a lot of theoretical and academic information which required more effort by the moderators to make the ideas more intelligible and more effort by participants to make sense of them and relate them to their own experience.

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- While preparing each meeting, moderators reported they needed more guidance and explanation about the content of several presentations and on several occasions, they needed to be in contact with the author of each presentation, which wasn't always feasible or there wasn't enough time left to do so. This added some stress to the preparation process.

3. CHALLENGES ENCOUNTERED

- The main challenge faced during the IPAT training activity was maintaining the commitment of participants to the training programme. A significant dropout occurred after the second meeting and eventually a core group of 8-9 participants remained constant for most of the remaining meetings.
- It was difficult to schedule a time convenient for all parents to attend. At the end, Saturday 11.00-14.00 was agreed, as most participants seemed to be available during this time, although it was still not convenient for everyone.
- Moreover, the 3-hours duration of each online meeting was tiresome for many participants.
- During the training sessions, there were some participants who tended to be more disruptive or participants who would digress in their comments from the main topic of each presentation or meeting (e.g., questions about national exams in a session that considers bullying or discussing issues about school and the Ministries involved in day care)
- Having four presentations in each meeting overall produced a large amount of information which was hard to digest within the time frame of 8 meeting in total.
- There was not enough time to allow longer interactions between participants or participants and moderators (especially in the first two meetings)
- Moderators felt pressured when participants expecting from them to know information which went beyond the scope of the presentation content.
- It was noted that fewer participants remained for the interactive activities, after the end of the four presentations. However, the ones who remained engaged deeply in the activities.

4. POINTS RAISED BY PARTICIPANTS AND MODERATORS

Participants

The overall feedback from the group was positive and high levels of satisfaction were reported. Participating parents stated that what they received during the meetings was useful and positive, providing help with a number of issues related to their daily lives and the way these are affected by having a child with autism. The information they received answered many of their questions and gave them an opportunity to create connections to other parents and develop new perspectives on how they approached their autistic child and autism in general. They all felt motivated to seek further information about the IPAT training activity topics. They highlighted the importance of the experiential activities, as they initiated valuable interactions between participants, sharing thoughts, emotions, experiences and information about various matters related to autism and the care of their autistic children. Hence, participants expressed the wish that all meetings had a more interactive character, even during the presentations. In this respect, they thought that one limitation of the programme was the time management issue that became obvious on some occasions and as a result the experiential exercises often took place after the scheduled time, with several participants going away and not taking part in the experiential activity process. Lastly, participants requested the presentations to be sent to them, especially those with links to supporting sites, etc., and to be informed about upcoming new actions of a similar nature in which they could participate in.

Moderators

Overall, moderators considered the whole experience to be a highly creative, constructive, useful and nevertheless, demanding process. The collaboration between the two moderators was excellent both in terms of preparation of the material and delivering the meetings together.

The challenges faced were mainly related to the time available for preparation, as in several cases the final form of the presentations reached them only a few days before the meeting. Moreover, some difficulties were faced in terms of time management in the meetings, due

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to the large amount of information in the presentations. It would have also been helpful to coordinate more closely with other partner countries and receive regular updates about any issues with the delivery of the IPAT training activity in each country.

5. SUGGESTIONS FOR MODIFICATIONS

- For any future delivery of the IPAT training activity it would be essential to incorporate the input from the moderators and get them more involved in the preparation process, allowing more time for them to go through the content of the presentations and the activities.
- It will be useful include more information, which is presented in an accessible manner and directly linked to real life issues. Likewise, more examples or instructions about important tools used in ASD can be included in the content of each meeting. This means shorter presentations, including essential information and allowing more time for questions, would be more appropriate for the future. Instead of having 8 meetings, the IPAT training activity can be extended to 10-12 meetings of two hours duration each. In this respect, information isn't presented in a compact manner and allows participants to reflect more on the ideas presented.
- Following on from the previous point, presentations need to be less academic and more adjusted to an audience of parents rather than professionals in autism. Information must be presented in an immediate, accessible and digestible manner. Moreover, the IPAT activity content needs to be adjusted to the reality of the country being delivered in (e.g. information about diagnosis – diagnostic tools used, procedure, professionals involved in each country)
- It is also essential to ensure the material and the delivery of each meeting are stimulating enough and have a more light-hearted undertone, in order to reduce boredom or fatigue and consequently, prevent any significant dropouts in the participants.
- Some topics that stirred up a lot of interest or not adequately covered could be further developed (e.g. information about how to deal with bullying or employment opportunities for children with ASD)

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- The 10' discussion should revolve around the content of the presentation (e.g. any clarification, queries, comments that participants may have.) If some of the participants initiate discussions about their own experiences that goes beyond the scope of the presentation, they need to be asked to bring these thoughts and share them in the last part of the meeting which is dedicated to their reflections and the sharing of their personal experiences.