

NEWSLETTER #1

June 2021

The IPAT Project

Individuals with Autism Spectrum disorders present difficulties concerning verbal and non-verbal social communication and interaction and restrictive/repetitive interests, behaviours or movements.

Parental training is one of the factors enabling the optimal adaptation of parents to their child's autism diagnosis, their ability to support the treatment and collaborate constructively with the respective professionals involved in the child's rehabilitation and special education programs. IPAT aims to increase awareness about the role and the importance of parental training in the global management of the needs of autistic people, to increase accessibility to effective training, to motivate parents to use a valid self-training approach at different stages of life, in order to advocate for the rights and social inclusion of autistic individuals and eliminating stigma.

IPAT aims to:

- train parents with an autistic child to decrease parental stress and improve their quality of life
- create an Integrative Parents' Autism Training-IPAT module and a digital self-training Tool-IPATT, to be used by professionals and parents.

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The focus group in Greece was conducted with five participants: four mothers and one father of autistic individuals, who were asked about their training needs and scope, content and instruments of a training program they would attend.



Greek participants underlined that what they would benefit most from in training is understanding what autism is. With regards to challenging behaviours, they laid emphasis on understanding them, instead of addressing them with a view to stopping them.

In addition, they would appreciate learning about the scientific progress of autism research and the available treatments and training of professionals. Parent's interaction with the child and the capacity to spend quality time with their child was also expressed as a training need.



Turkey



3rd March 2021



The interviews were conducted with a total of 6 families as two focus groups including 3 people in each focus group. In order to obtain more in-depth information from the participants, attention was paid to the fact that they consist of individuals who differ in terms of gender and children's support needs.



Participants drew attention to the importance of issues such as increasing knowledge awareness about autism, providing professional support, focusing on what can be done to socialize children, and providing children with self-care skills.

The subjects stated by the participants are compatible with the reality of the project in terms of increasing the quality of life of individuals with autism and their families. Generally, the participants agreed on the issues mentioned and stated that they are ready to take on the necessary role for the education of their children.

The Research: the Focus Groups



Italy



20th March 2021



Seven families of people with autism participated. The group was diverse based on sex, geographic distribution and severity degrees of support needs. The families expressed their pleasure for being part of the project and their interest in continuing to advance in the role of families as main support of their relatives.



Two of the aspects that stood out the most were:

- the need to improve coordination and communication between professionals and families
- training regarding legal aspects that contribute to autonomy, independence and the guarantee of a secure future for their sons.

The group showed some discrepancies regarding the role of parents as therapists of their children, many claimed the role of parents, however, aware of the need to have tools, strategies and training to facilitate knowledge and coexistence with their sons.



Spain



18th February 2021



The group was diverse based on sex, geographic distribution and severity degrees of support needs of the families children. The atmosphere of welcoming allowed people to open up and share their experiences and thoughts in a spontaneous way, all of them expressed their joy for having taken part in the research of IPAT project.



The families agreed on different needs:

- become aware of what are the rights and guarantees at national level of their children
- conducting and maintaining social life administration of daily domestic life and most of all the management of unforeseen events would definitely bring benefit to the whole family.

All the families had the desire to participate in a training program. For them, this should not be just theoretical. The issue of job placement turns out to be very important. Parents agreed in dealing with the painful and frustrating theme of "after us".

The Research: Joint Report

The research outcomes of the IPAT project consist of a bibliographical and a qualitative research of the training needs of parents of autistic individuals. They comprise a Literature Review and a Global Report.

More specifically, the Literature Review was conducted between November-December 2020. It reviewed the existing research on the training needs of parents of autistic individuals, covering the past twenty years of relevant studies, qualitative, quantitative and mixed, with greater emphasis on the past decade (2010-2021). More than 50 relevant studies were reviewed and the following conclusions were reached: autism is a neurodevelopmental disorder with specific needs and characteristics; parents of autistic individuals are the main stakeholders involved in the care provision of their children; children, parents and families' emotional wellbeing is impacted significantly, often expressed as higher stress, depression and anxiety or lower quality of life, compared to parents of individuals with other disabilities or neurotypical children; parents' main concerns are child-specific (e.g. behavioral, cognitive, communicational) or family-specific (e.g. marital relationships, financial burden); parents' training needs have been investigated to a minimal extent and on a quantitative basis; there is need for more in-depth investigation of their own views on their training needs.

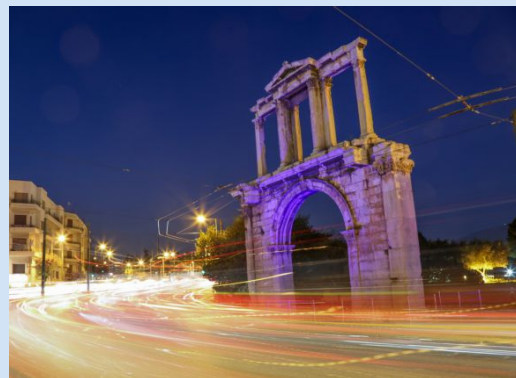
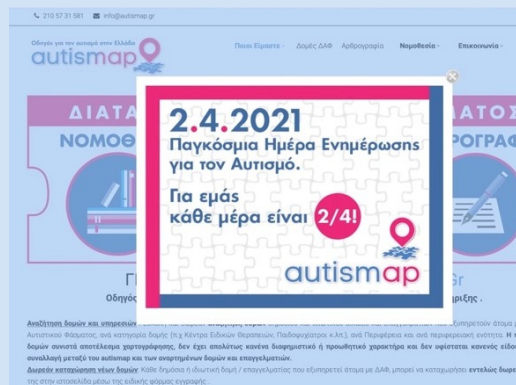
Based on those conclusions, focus groups were conducted in the four countries of the project between December 2020-April 2021, with 23 participants (parents of autistic individuals of a wide spectrum of ages and levels of functionality). They were asked about their training needs and the scope, content and methodology of a training program that would address them. The four focus groups were transcribed and analyzed with the method of thematic analysis, leading to 10 themes, eight of which concerned the content and two of which concerned the methodology of a training program that would be designed and addressed to this population. The eight themes that concern the content were: 'understanding autism', 'psychological distress and impact on the family', 'social communication, interaction and skills', 'understanding and managing specific behaviors', 'child and parent interaction', 'social inclusion and autonomy', 'sexuality' and 'rights, legal and institutional issues'. The two themes that concerned the structure and the methodology of the training were: 'structure of training according to age and levels of functionality' and 'methodology of training and practicalities'. The majority of findings confirmed and strengthened the conclusions of the Literature Review, whereas some of them deepened further our understanding of those. On the other hand, some themes described new topics, which had not been identified in previous research, concerning both the content and the structure and methodology of training.

The World Autism Day 2021

The United Nations General Assembly unanimously declared 2 April as World Autism Awareness Day to highlight the need to help improve the quality of life of those with autism so they can lead full and meaningful lives as an integral part of society.

Greece

"For us, every day is April 2nd". Using this motto, Child and Adolescent Centre has enhanced its ASD community awareness activities during the month of April: we have dedicated our monthly Newsletter to autism, we have published an interview on autism in Greece and in Europe on the Social Policy website and press releases on local newspapers, we have used the social media and all our channels to promote autismap.gr, the first information portal on autism in Greece developed by our organisation, we have made advances in broadening our synergies and collaborations with other organisations of the civil society supporting autistic individuals. At the national level, the Hellenic Association for the Protection of Autistic Individuals, in collaboration with the Ministry of Civilisation and the municipalities of Athens, Piraeus and Ioannina, has participated in the initiative Light it Up Blue. Several monuments and buildings were illuminated in blue.



Turkey



Important iconic buildings in our country were illuminated with blue light on April 2 within the scope of the "Light Autism Blue" campaign, which is organized simultaneously all over the world in order to draw attention to autism and increase awareness.

Gaziantep University also tried to be a part of this meaningful awareness movement by turning blue light on autism in our home during this period when the "Stay at Home" call was made. We also participated to a Radio Programme to present the IPAT project.

Spain



Through the campaign slogan “I can learn. I can work”, Autism Spain promoted education and employment, claiming that the educational system and the labour market do not adjust to the specific needs of people with autism. The risk of being excluded in these areas has been increased through the pandemic.

Autism Spain as global movements asked citizens to make a gesture for autism and join the awareness campaign on social networks in 3 simple steps:

1. Pick a tool that represents one of your skills and hold it in your hand
2. Take a picture, video or gif by holding or using the tool
3. Share it on your social networks with the hashtag #WorldAutismDay



Italy

Controvento has launched the initiative of bring together all the realities, associations and enterprises that work with young people with ASD in the area of Catania city, to create a network of collaboration to work for a common goal, regardless of differences . The purpose have been to offer on a large scale (parents, professionals, locals) training pills by create free program during the month of april and may in autism field.



"Uniti per l'autismo" (United for autism) aimed at creating social infrastructures that make the territories inclusive.

Activities in primary schools: Controvento has promoted some educational activities on the topics of autism and inclusion. It was vert appreciated by all classmates of the children with ASD.



What's next?

The findings from both the literature review and the focus groups have been used in the formulation of suggestions for the development of the IPAT module, whose design is currently in progress, with a view to the training of 64 parents of autistic individuals (16 participants from each one of the four partner countries) taking place in January-April 2022.

IPAT project partners are now working on the development of the IPAT module that will touch on the ten themes identified during the research. The content will be organized in a 24 hours' training activity and it will be translated into the 4 languages of the partner countries. After the end of the Parents' training activity, IPAT partners will implement evaluation and assessment sessions that will refer to the challenges encountered, country specific particularities, potential cultural issues raised, lessons learnt, remaining needs, suggestions for adaptation of the IPAT module. In this way, the material developed will respond to the needs of parents and will be transferable to other contexts.

Parallely, the Integrative Parents' Autism self-Training digital tool-IPATT- structure and content, will be developed based on the IPAT Module and the respective needs assessment carried out during the research, in association with our previous experience and expertise. The digital-technical part will be developed as an interactive user-friendly platform to assist the acquisition or refreshment of knowledge, skills and attitudes while allowing the identification of remaining training needs. The content will be presented in an appropriate form, promoting interaction and it will be made available in the four languages of the partner countries.

The next months of the IPAT project will be devoted to the development of the content in preparation for the parents' training planned for the beginning of 2022. Plenty of resources and opportunities are going to be shared by the IPAT partnership, stay tuned and share the upcoming news with your network.

Follow the IPAT project on our online channels!

