

Integrative Autism Parents' Training IPAT IO4/Report Testing of the IPAT self-learning digital tool-IPAT-T.



Coordinator



Partners





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Introduction

The digital self-training tool- IPATT is one of the outputs of the EU co funded Erasmus+ program 'Integrative Parents' Autism Training'-IPAT implemented with the collaboration of 5 partner organizations active in autism service provision, in Greece, Spain, Italy and Turkey.

Within the Intellectual outcome 3 of the Integrative Parents' Autism Training (IPAT) program, we developed the Integrative Parents' Autism Self-Training digital tool-(IPAT-T): Autism self-training tool for parents is a user-friendly Digital Tool developed in Moodle, to support self-learning of parents with an autistic child; Autismo Burgos was the leading partner of IO3.

The IPAT self-learning digital tool aims to provide parents and careers of autistic persons with knowledge and skills, in order to improve their understanding about their child's specific needs, to support them in their parental role and in shaping their attitude towards the rights, needs and abilities of their child on the autism spectrum and those of the entire family.

The IPAT digital tool consists of 31 videos, 31 short presentations and corresponding activities-exercises; the tool is available in English, Greek, Turkish, Spanish and Italian. The material is organized in the following 8 thematic meetings (lessons): "What is autism", "Therapeutic approaches", "Lived experience of the family", "Child- Parent interaction", "Social inclusion and autonomy", "Adolescence and adult life", "Legal issues and rights", "Practical guidance and useful tools- Prevention and management of accidents and health issues". The IPAT self-learning digital tool-IPAT-T was developed based on the IPAT Training Module-IO2- taking into account the needs of parents, as expressed by themselves at the beginning of the project-IO1-. At the end of each meeting- lesson, users may take the respective quiz and evaluate what they have learned or what they still need to focus on. Experienced professionals working with persons on the autism spectrum and their families participated in the preparation of the material.

As described in the project initial design, the self-Training digital tool-IPATT- was tested with a total sample of 80 parents with a child on the autism spectrum, in order to assess their satisfaction with the tool and perceived usefulness, as well as, to generate feedback for necessary adaptations and finalization of the tool.

Methodology

Procedures

Testing of the IPAT-T took place simultaneously in all partner countries, from 31/3/2023 to 13/4/2023. In Greece, Spain and Italy, national multiplier events organized at the same time period were used to promote the use of the tool and recruit parents for testing it. Although considered highly improbable after the disastrous earthquake that hit Gaziantep in February this year, our Turkish colleagues successfully implemented the testing of the digital tool in Turkey against all odds. Child and Adolescent Centre was in charge of IO4, thus, for the design and implementation of the satisfaction survey. All partners participated in data collection and data entry.

Parents were invited to 1. Use the tool 2. Take the satisfaction survey in google forms, in order to provide feedback on their satisfaction with the tool and its perceived usefulness, identify difficulties potentially encountered or unmet needs and formulate suggestions for improvement.

Participants

Participants were parents with a child on the autism spectrum, willing to use the IPAT-T tool and take the satisfaction survey, without limitation as per the child age or time from diagnosis. During the IPAT-T testing phase, 3971 visits to the IPAT-T tool were recorded and 556 individual users.

Data collection

Data collection for the satisfaction survey lasted till April 22nd 2023.

We developed a survey specific self-administered questionnaire, with 24 questions. The first seven questions were used to collect socio-demographic and clinical data of participants and their children (age, gender, time from delivery of child's diagnosis, child's participation in rehabilitation program, child's enrollment in a special education program, parents' exposure to counseling / psychotherapy / psychoeducation sessions, number of the IPAT-T modules used). The following 13 questions focused on parents' satisfaction and perceived usefulness of the digital tool: five of them- satisfaction- were scored in a Likert scale from 1 to 10 (1= Not satisfied at all, 10= Totally satisfied) and eight- perceived usefulness- were scored on a 1 to 5 Likert scale (1= Totally disagree, 5= Totally agree); the last four were open ended questions: participants were asked about their perception of the most "positive" and "most negative" aspect of the digital tool, about unmet needs they would have wished the digital tool to have covered and suggestions for improvement.

Participants received the questionnaire in a google forms link; each completed questionnaire was attributed a unique anonymous code.

Partners were provided by the coordinator with a data entry excel file, data from all countries were compiled into a single excel file and analyzed using the Statistical Package for Social Sciences IBM SPSS 22.0

Ethics and personal data protection

Participation in the survey was anonymous and voluntary. Data collected were anonymized and accessible only to the research team exclusively for the purpose of the survey. Necessary procedures were put in place for personal data protection. Invited parents were informed in writing about all the above; in addition, they were informed that their participation should be the result of free will, without any interference with the care and services provided to their child or themselves. Similarly, it was shared that by participating in the testing, they would actively contribute to the finalization and optimization of a self-learning digital tool to be used free of charge by many other parents in their country and other countries, in Europe and worldwide.

Results

Of the 556 individual users of the IPAT-T tool during the 2 weeks testing phase, 80 of them took the satisfaction survey, response 14%. Descriptive results are presented in tables 1-4.

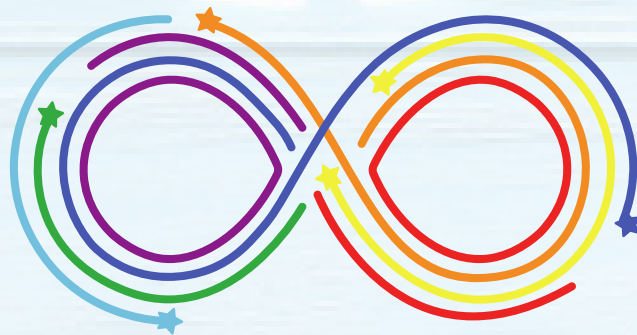


Table 1: Demographics and characteristics of participating parents, by country

		Total	Greece	Spain	Italy	Turkey
Population N/%		80	16 / 20	14 / 18	25 / 31	25 / 31
Age (Parents)	Mean / SD	42.01 / 6.49	44.37 / 6.57	46.78 / 6.34	43.16 / 4.87	36.68 / 3.87
Gender (Parents)	Male	26 / 32,5	1 / 6	7 / 50	7 / 28	11 / 44
	Female	54 / 67,5	15 / 94	7 / 50	18 / 72	14 / 56
Age (Children)	Mean / SD	10 / 5.58	12.66 / 6.79	12.35 / 8.05	6.88 / 3.24	10.44 / 2.63
Gender (Children)N/%	Male	57 / 77,4	12 / 80	9 / 64	20 / 80	16 / 64
	Female	14 / 22,6	3 / 20	5 / 36	5 / 20	9 / 36
Number of years since diagnosis	Mean / SD	5.82 / 5.02	7.66 / 6.84	7.21 / 7.26	4.04 / 2.80	5.72 / 2.83
Child Participation in therapeutic/educational /rehabilitation programs	Yes	69 / 86,3	13 / 87	11 / 79	25 / 100	20 / 80
Parent participation in therapeutic programs (nowadays or in the past) *	Parent counseling	60 / 77	15 / 94	6 / 43	22 / 96	17 / 68
	Parents psychoeducation	17 /22	0	2 / 14	0	15 / 60
	Family/couple therapy	16 / 20	0	0 /	0	15 / 60
	Psychotherapy	18 / 23	1 / 6	1 / 7	1 / 8	16 / 64
	Other activity for parents of children with autism	36 / 46	0	10 / 71	1 / 8	24 / 96
Number of modules of the digital self-education tool parents use	1-3	15 / 19	9 / 56	2 / 14	4 / 16	0
	4-6	28 / 35	1 / 6	2 / 14	18 / 72	7 / 28
	7-8	37 / 46	6 / 38	10 / 72	3 / 12	18 / 72

Values are presented as N / % and Mean / SD unless stated otherwise

SD: Standard deviation

* Participants were able to choose more than one answer

Table 2: Satisfaction with different aspects of the digital tool, by country

	Total	Greece	Spain	Italy	Turkey
Overall satisfaction	7.35 / 2.11	7.12 / 2.02	5.92 / 3.26	6.72 / 0.66	8.92 / 1.09
Expectations met	6.96 / 2.20	7 / 2.42	5.71 / 3.21	6.28 / 0.82	8.32 / 1.46
Ease of use	7 / 2.23	7.12 / 2.49	5.57 / 3.01	6.12 / 1.07	8.6 / 1.13
Videos	6.96 / 2.39	6.87 / 2.80	5.78 / 3.25	6.12 / 1.39	8.52 / 1.23
Presentation s	7.28 / 2.22	7.18 / 2.62	6.64 / 2.91	6.20 / 1.23	8.8/ 1.2
Interactive activities	7.02 / 2.31	7.18 / 2.29	5.5 / 3.22	6 / 1.05	8.8 / 1.13
Global Satisfaction Score	7.09 / 2.25	7.08 / 2.46	5.85 / 3.17	6.24 / 1.09	8.66 / 1.23

Values are presented as Mean / SD

SD: Standard deviation

Scoring on a 1-10 scale, 1: lowest, 10: highest

Table 3: Perceived usefulness of the digital tool, by country

		Total	Greece	Spain	Italy	Turkey
Using the digital tool contributed/may contribute to strengthening/enriching their existing knowledge		3.83 / 1.02	4 / 0.36	4 / 1.41	3.08 / 0.89	4.4 / 0.63
		3.78 / 1.07	4 / 0.36	3.78 / 1.42	3.08 / 0.93	4.36 / 0.84
helped me understand more about my child's autism		3.55 / 1.14	3.8 / 0.65	3.28 / 1.43	2.76 / 0.90	4.36/ 0.74
contributed / may contribute to improving the creative time I spend with my child		3.48 / 1.13	3.53 / 0.80	3.07 / 1.38	2.72 / 0.82	4.44 / 0.57
contributed / may contribute to reinforcing my skills in managing my child's behavior		3.46 / 1.24	*	3.28 / 1.48	2.6 / 0.89	4.44 / 0.49
contributed / may contribute to the improvement of our relationships within the family		3.36 / 1.09	3.6 / 0.61	3.14 / 1.40	2.72 / 0.91	4 / 0.84
helped me/may help me get more support from the wider social environment		3.46 / 1.18	3.4 / 0.8	3.07 / 1.48	2.76 / 0.86	4.44 / 0.75
promoted my knowledge about the rights of my child and those of the whole family		3.44 / 1.11	3.86 / 0.61	3.28 / 1.38	2.56 / 0.80	4.2 / 0.69
Global Perceived Usefulness Score		3.55 / 1.14	3.79 / 0.69	3.38 / 1.49	2.85 / 0.92	4.35 / 0.71
I will recommend the digital tool to other parents/carers		3.93 / 1.12	4.13 / 0.80	3.57 / 1.67	3.4 / 0.93	4.56 / 0.63
Participants who agreed / strongly agreed that they would recommend the tool to other parents	N / %	57 / 79	13 / 81	9 / 64	12/ 48	23 / 92

Values are presented as Mean / SD, unless stated otherwise

SD: Standard deviation

Scoring on a 1-5 scale, 1: Totally disagree, 5: Totally agree

*Missing values correspond to the Greek participants, as this item had erroneously not been included in the Greek version of the questionnaire.

Table 4: Grouped comments of open questions, by country

		Greece	Spain	Italy	Turkey
Content	Positive comments	7 / 32	10 / 42	12 / 24	7 / 46,5
	Negative comments	9 / 41	6 / 25	5 / 10	4 / 27
Technical	Positive comments	5 / 23	3 / 12	13 / 25	3 / 20
	Negative comments	0	5 / 21	20 / 39	1 / 6,5
Other	Positive comments	1 / 4	0	0	0
	Negative comments	0	0	1 / 2	0
	Total	22	24	51	15

Values are presented as N / %

Starting with the positive comments, as for the content of the Integrative Parents' Autism Self-Training digital tool, participants refer to it as "Easily accessible and very useful, especially for parents who may be confronted with the problem for the first time", "a tool that covers all aspects of the ASD" and "provides comprehensive information on all topics and issues related to our child and his or her physical and emotional perception/environment". Furthermore, it is "equipped with up-to-date information created by experts and ideal for self-parent education" while "short modules allowed the participants to complete the course and not have the feeling of not progressing and becoming tiresome". As for the positive comments about technical issues, participants focus on the fact that "you can go through the course at your own pace by logging into the course at any time", and "it gives parents time to process the material and come back whenever they wish". Moreover, the fact that it is "available for free" is another positive aspect. Last but not least, the one positive comment which was included in the "Other" group category, briefly captures the overall experience of using the tool stating that it offers "support to the parents".

Focusing on the negative comments, as for the content of the Integrative Parents' Autism Self-Training digital tool, some of the participants said that they found it difficult that the videos were not dubbed but they were in English language. Others said that there was "too much theory and not enough practical examples to solve day-to-day problems". In addition, participants referred on some aspects which they wanted to be further analyzed in the context of the presentations, such as "what is provided by each country's authorities for autistic people", "issues of siblings of children with autism", "More defined aspects for adolescents, adults" etc. As for the negative comments about technical issues, several participants mentioned "that access in the platform and viewing the course on devices other than the computer is very poor, encouraging you to only take the course on the computer". Moreover, participants also reported that the existence of subtitles in their language while the videos were in English, made it harder to watch instead of making it easier for them. Finally, the one negative comment which was included in the "Other" group category, reports that "the answers to the final tests must necessarily be related to the videos and not to the personal situation of one's own children. Often they do not coincide".

Comments differed or clustered across partner countries:

- most of Italy negative comments refer to technical issues: the difficulty to use it on mobile phones
- most of Turkey demands refer to practical issues
- comments from Spain mostly refer to technical issues, such as quality of videos and mobile device accessibility, and contents with a lot of theory and little practice
- different demands depending on the countries: in Greece they ask for more detailed information on state and private support; in Turkey they ask for the administrative steps to follow; in Italy they want more information on the best centers or specialized departments or sports activities.

Suggestions for improvement formulated by users:

- to include recommendation of the tool from official organizations
- to include, however briefly, specific topics that embrace the full spectrum and different areas of daily life: work, leisure, sports...
- to include practical experiences and testimonies from other parents
- to include practical tips about management of challenging behaviors
- video style must be less formal, language less scientific and more practical
- videos must be recorded in each language, plus one version in English



Discussion

We have developed the IPAT self learning digital tool for parents with a child on the autism spectrum and tested it with the participation of 80 parents in 4 countries. We have assessed the satisfaction of participants and their perceived usefulness of the tool. During the testing phase of 2 weeks duration, almost 4000 visited the IPAT-T tool and 556 used it, while 14% of the latter participated in the satisfaction survey. We consider that the number of visits and users in this short time period underlines the interest raised by the tool and its dynamic, as well as the short term impact of dissemination and recruitment activities implemented by partner organizations; the response - participation proportion of 14% was rather low, however, we have been able to exceed by 33% the expected number of participants as included in the initial design - 60.

Our sample consisted mainly of twice as many mothers than fathers, in their early or mid-forties , Turkish participants being younger, in their thirties; participants had experienced life with their child's autism diagnosis for an average of almost 6 years before taking the survey, the majority- 77%- had already been exposed to parentcounseling activities, ranging 45-96% across countries, a smaller proportion of around 20% to psychoeducation, family therapy of psychotherapy , mainly represented by Turkish participants; almost half of the survey sample- 46%- used almost all modules of the tool ,72% of the Spanish and Turkish participants, more than one third- 35%- had been using more than half of the modules , while 19% up to 3 modules; their predominantly male children's (Male/female ratio 3,5) age was 10 years on average, ranging 6-12, the vast majority of them - 87%- being enrolled in therapeutic/rehabilitation or education programs.

Participating parents were moderately satisfied with the use of the tool: overall satisfaction 7,35/10, ranging 5,9 -8,9 across countries, global satisfaction score 7/10 ranging 5,85-8, slightly less satisfied with the videos; Turkish participants were the most satisfied and Spanish the less satisfied, this pattern persisted across almost all satisfaction items but one. Similarly, participants perceived the tool as moderately useful, global perceived usefulness score being 3,5/5, ranging 2,85-4,35; perceived usefulness was highest for Turkish participants and lowest for Italian ones; however, intention to recommend the tool to other parents was clearly positive: parents scored their agreement to recommend the tool to other parents with 3,9/5 on average, ranging 3,4-4,5 across countries; 79% of participating parents agreed or strongly agreed that they would recommend it to other parents.

We have received 24-26 positive and negative comments related to content or technical issues respectively, i.e. almost one third of participants formulated some positive or negative comment; it seems that Italian participants had encountered most technical aspects challenges; unmet needs were quite different across countries; it seems that videos in native language would have been necessary for some participants, while access from mobile phones proved challenging for several others.

Content wise, this experienced parents' sample, already exposed to counseling, managing their child's diagnosis for several years, would probably need more topic specific and skills' development oriented material; the tool materials were adapted from the IPAT module that had been developed based on the parents' expressed needs; nevertheless, exchange of views and experience between parents is not possible in IPAT-T as it occurred during the IPAT Training activities using the Module, thus, potentially limiting the added value rising from shared experience. In addition, tailoring to specific needs is not possible due to its current static structure.

According to the comments received, we have proceeded to several modification and testing activities: Review of videos loading, Presentation of instructions to access to Moodle from mobile devices, Speed test of the platform. We have modified several presentations accordingly to the feedback provided by parents at the satisfaction surveys.



Conclusions

The IPAT-T self-learning tool has been developed and tested in a transcultural context, as described in the initial IPAT project design; the tool is now available after final revision tool.ipatproject.eu, in English, Spanish, Italian, Greek and Turkish, as an Open Educational resource under Creative Commons Attribution license.

Participants, already trained parents, several years after having received their child's autism diagnosis, considered the tool to be rather useful, were rather satisfied with IPAT-T and would definitely recommend it to other parents in their vast majority; the tool would potentially benefit more non otherwise trained parents and/or sooner after receiving their child's diagnosis; it may also be used as an introduction training material after diagnosis and preceding psychoeducation or other parents' support activities; the tool material may be enriched in the future by adding specific context related to work, leisure or other daily life activities and management of behaviors that cause concern. We have used the feedback provided by participants in order to finalize the IPAT self-learning digital tool IPAT-T.

