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PARENT EDUCATION FOR MACEDONIAN FAMILIES LIVING WITH AUTISM SPECTRUM DISORDER: THE ESIPP PROJECT

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Abstract

Educating parents of children with ASD about the condition benefits both child and family. However, such programmes are typically unavailable in South-east Europe. To address this, the ESIPP project developed, provided and evaluated education in autism to over Croatian, Cypriot and Macedonian parents. A parent education curriculum and locally differentiated materials were developed, as well as recommendations for European policymakers.

This paper describes and discusses activity undertaken within the project to develop and deliver training to Macedonian families.

Key words: Parent education, autism spectrum disorder, family support

Introduction

Living with ASD

Living with disability is acknowledged as challenging, and can be lead to stress within families, affecting family wellbeing (Dempsey *et al.*, 2009). This is particularly true in the case of families living with autism spectrum disorder (ASD) (Davis & Carter, 2008). The characteristic features of ASD – difficulties and differences in social communication and interaction, restricted and repetitive interests, sensory sensitivities – can impact in all areas of family life, restricting social inclusion, achievement and fulfilment for all family members (Hayes & Watson, 2013; Schaaf *et al.*, 2011).

Children with ASD have specific and special needs arising from their autistic characteristics. As a result, parenting behaviours that are effective with typically-developing children may be inappropriate to meet their needs (Keen *et al.*, 2010). Further, due to the diverse nature of ASD, no single intervention strategy is suitable for all (Charman *et al.*, 2011). This can leave parents feeling disempowered and de-skilled, impacting negatively on family functioning (Altiere & von Kluge, 2009).

Social support is a significant moderator of stress caused by the presence of ASD (Luther *et al.*, 2005). However, families living with ASD receive limited informal social support (Preece & Jordan, 2007); while the effectiveness of formal support is dependent on the skills and expertise of local professionals (Whitaker, 2007).

This can be problematic where there is a low awareness and understanding of ASD, and where services and professional training are limited. Such is the case across South-east Europe, including this country (Daniels *et al.*, 2017; Trajkovski, 2017; Troshanska, 2015).

Parent education in ASD

The internet can be a source of helpful information about ASD, but identifying good from bad, accurate from fake, can be a difficult task (Mansell & Morris, 2004; Offit, 2008). This is particularly the case when parents may be feeling distraught and desperate and are perhaps seeking for knowledge in a language which is not their first language (Clayman *et al.*, 2010). An internet search undertaken today (7 May 2018) on Google using the key words ‘autism’ and ‘treatment’ had almost 4.5 million results; a search for ‘autism’ and ‘cure’ had over 600,000 results. It is unsurprising that parents can feel overwhelmed and so ensuring that parents have access to accurate and truthful information is extremely important. Providing accurate information and teaching effective strategies has been shown to improve parent and family well-being and functioning, as well as supporting the development of the child with ASD (Farmer & Reupert, 2013; Ji *et al.*, 2014). Preece and Trajkovski (2017) reviewing the literature regarding parent education in ASD identified a wide range of positive impacts including reductions in anxiety and stress, and improvements in coping, parent-child interaction and communication, understanding of ASD, parental efficacy and confidence and parental quality of life. However, as with broader family support services, parental education regarding ASD is limited or non-existent in many areas, including South-East Europe (Delfos, 2010; Hansen *et al.*, 2017; Salomone *et al.*, 2015).

Equity and Social Inclusion through Positive Parenting: the ESIPP project

To begin to address this situation, a three-year project (2015-18) was established to make parent education about ASD available to Croatian, Cypriot and Macedonian families. The project, named *Equity and Social Inclusion through Positive Parenting* (ESIPP), included academics, professionals and parents from across Europe, and was led by the University of Northampton. The Macedonian Scientific Society for Autism was a key partner in the project, undertaking all activities relating to the development of services for Macedonian families. The project was funded by the European Union and was designed to:

- develop an evidence-based model for delivering parent education in ASD that can be used across Europe
- develop a core curriculum and locally appropriate and differentiated parent education training materials
- use these materials to provide parent education to families living with ASD in areas where it has been previously unavailable or difficult to access
- evaluate the effectiveness of the materials and the impact of the training using quantitative and qualitative data collection and analysis

- share the model curriculum, tools and materials with stakeholders and make recommendations to policy- and decision-makers.

This paper reports particularly upon the first three objectives. It discusses how the parent education model, core curriculum and materials were developed, and the training events provided to Macedonian families. Issues relating to the provision of training are considered and the importance of ensuring continued parent education is identified.

Methodology

A collaborative, action-based methodology (Gray, 2018) was used to undertake the development, delivery and evaluation of the ESIPP project. Activity necessary for the successful delivery of the project comprised:

- Identification of the parent education programme content
- Identification of the parent education programme delivery process
- Development and differentiation of the training materials in each project language
- Training of local trainers in the three project countries
- Provision of training to parents within the three countries
- Evaluation of the project
- Development of policy recommendations regarding parent education in ASD
- Dissemination of information with regard to the project, to raise awareness regarding parent education in ASD and to promote the sustainability of parent education within the countries.

The project was evaluated via a combined process and outcome evaluation methodology (Royse, Thyer & Padgett, 2009) utilising a multi-phase mixed methods design (Creswell & Plano Clark, 2011). Multiple data collection methods were used to gather data from parents, trainers and stakeholders, including questionnaires, interviews, focus groups and reflective diaries.

Identifying the core curriculum

An anonymous structured questionnaire was developed by the partners to identify parents' attitudes and opinions regarding delivery of parent training (timing, length of sessions, potential barriers) and training content. Questionnaire design was informed by a review of the literature regarding parent education in ASD (Preece & Trajkovski, 2017) as well as an internet search of existing training models. Twenty-seven training topic areas were identified, within six domains. These were:

- Awareness and general information
- Communication
- Specific approaches
- Self-care and behaviour

- Socialisation and relationships
- Leisure and recreation.

In total, 266 questionnaires were distributed to Croatian, Cypriot and Macedonian families, and 148 were returned, a response rate of 58%. Fifty Macedonian families were surveyed with 38 responses. This 76% response rate was the highest across the three countries and was seen as indicative of interest in parent education. Respondents came from a range of geographical settings across the country: Skopje (n=23), Kavadarci (n=5), Gevgelija (n=4), Stip (n=3), Negotino (n=1), Prilep (n=1) and Tetovo (n=1).

Training topics

Analysis identified a high level of variation across the three countries regarding training topics prioritised (Preece *et al.*, 2017), with chi-square analysis identifying significant differences between the three countries regarding 13 of the 27 topic areas across all six domains. Macedonian parents expressed an interest in a far higher number of topics (n=21, 72%) than their counterparts in Croatia (n=12, 41%) or Cyprus (n=8, 28%): their prioritisation of topics is shown in Table 1. It was felt that this may reflect parents' prior engagement with and knowledge about therapeutic approaches and services, which are more developed within Cyprus and Croatia. This could mean that Macedonian families had less access to information and training than their counterparts in the other two countries.

Table 1: Macedonian parents' training priorities (n=38)

Topic	No	%
Strategies on facilitating my child's interaction with other children	35	92
Policy, legislation and rights	35	92
Strategies for enhancing my child's communication	32	84
Sensory integration and development	31	82
Structured approaches (e.g. ABA, PECS, TEACCH)	31	82
Identifying and/or developing socialization opportunities	31	82
Strategies on dealing with sexuality and relevant adolescence issues	30	79
General knowledge and information about autism	29	76
Methods of high tech alternative communication (AAC): (e.g. digital devices)	29	76
Strategies on working on daily routines (toilet, sleep, etc.)	29	76
Issues on family's socialization and social life	28	74
Awareness and help in the community	27	71

General information on behavioural management strategies	26	68
Methods of no & low tech alternative communication (AAC): (cards, boards, signing)	26	68
Strategies on changing specific behaviours at home and in the community	26	68
Improving communication at home	25	66
Issues of sexuality and/or relationships	25	66
Structuring the home environment for safe and interesting leisure activities	24	63
Strategies on developing child's self-care skills	24	63
Strategies on facilitating my child's interaction with other family members	23	61
Structuring home environment to support skills development and behaviour	23	61
Strategies to raise awareness in family and friends	21	55
Strategies on managing aggressive and/or self-injurious behaviour	20	53
Coping and emotional response to living with autism	20	53
Interactional approaches	2	5
Going to doctor/dentist	0	0
Positive behavioural support	0	0

Barriers to training

A number of barriers were also identified within the survey. Fifty-five per cent of Macedonian parents (n=21) identified their work schedules as being potentially problematic, with only 21% (n=8) identifying that they would have no difficulty attending training. Half of the parents from Macedonia (n=24, 50%) expressed a preference for evening training sessions. However, for logistical reasons associated with the funding of the project, it was not possible to provide training in this way. As with parents from Croatia and Cyprus, parents expressed a strong preference that training should take place locally (n=38, 100%)

'Positive Approaches to Autism': the ESIPP parent education programme

Work on the development of the parent education curriculum and training materials commenced in December 2015, with partners from the Macedonian Scientific Society for Autism (MSSA) working alongside colleagues from Croatia, Cyprus and the UK. The programme consists of six modules and is designed to be delivered over 12 hours (6 x 2 hours). The modules are as follows:

- Module 1: Introduction to ASD
- Module 2: Practical Strategies to Manage Behaviour through Visual Structure
- Module 3: Managing Sensory Sensitivities
- Module 4: Exploring Communication and its Impact on Behaviour
- Module 5: Positive Approaches to Social Development and Interaction
- Module 6: Understanding and Managing Challenging Behaviour.

The training was designed to utilise a number of pedagogic approaches, including lecture format, group activities and question and answer sessions, as well as offering opportunities for individual consultation. Coordination of the curriculum and materials was undertaken by the project's external 'expert trainers' from Target Autism in the UK and Autism Assessment Support Practice from Cyprus. These trainers had a wealth of experience of delivering parent education and training within a number of models, including the 'TEACCH' structured teaching model (Mesibov et al., 2005) and the UK National Autistic Society's 'EarlyBird' approach (Shields, 2001). Materials were locally differentiated and translated into Macedonian by the MSSA.

Parent education events for Macedonian parents

The ESIPP project was designed in such a way that the initial parent education sessions would be led by external trainers, with support and translation provided by local staff, who would be trained to deliver the training themselves. Target Autism led the events in Skopje at which the first cohort of parents were trained; AASP led the second event. The final four sets of ESIPP parent education sessions were led by local MSSA trainers. Five local trainers – teachers and academics who were members of MSSA – were trained to deliver the parent education material. External trainers were highly impressed by the skills and commitment of the local team.

"The shadow trainers, they knew what they were talking about. They had a good background, they knew what it's about."

"I was amazed at how skilled they are. So many of the teachers we encountered have PhDs or Masters degrees, in the classroom, you know... I was just blown away by how much knowledge they had."

In total, six groups of Macedonian parents were trained during the project lifetime (n=70). Initial trainings took place within Skopje. This was easier for external trainers to travel to, and the MSSA partners had ready access to premises and equipment. This was also the country's main population centre, where there was a known population of children with ASD (Ministry of Education and Science, 2015). After these initial events, the ESIPP project was taken from the capital city across the country, offering parent education to families in Veles in the centre of the country, Ohrid and Bitola in the south and Debar in the east (see Table 2). In addition

to the core curriculum, additional non-core modules (regarding sleep issues, food and eating, and puberty and adolescence) were provided by staff from Target Autism and the University of Northampton at events in Skopje and Ohrid.

Table 2: ESIPP parent trainings for Macedonian parents

Date	Location	Number of parents trained
March/October 2016	Skopje	20
February 2017	Skopje	16
June 2017	Veles	10
September 2017	Ohrid	11
October 2017	Bitola	8
February 2018	Debar	5

Challenges and issues

At the ESIPP national conference held in Skopje in November 2017, 97% of participants felt there was a national need for parent education in ASD, while 100% agreed that the project had valuable goals. The formal evaluation of the Macedonian parents' experience, and the impact of the training upon them, is not discussed within this paper, but parental feedback and comment has been extremely positive and it is clear that the project has been valued by them.

However, this does not mean that the project has faced no challenges. Parents of children with ASD face many pressures and attending training can be problematic when juggling other responsibilities. Previous research into parent training has identified that parents may 'drop out' of training (Nix *et al.*, 2009), and parent socio-economic status and the availability of support have been identified as particular factors impacting on attendance (Baker *et al.*, 2011). Belonging to a minority ethnic community can also impact negatively on attendance (Mendez, 2010). This was identified in ESIPP as a particular issue when the training was taken to settings such as Ohrid and Debar, where attendance and engagement by parents from within the Albanian Muslim communities in these cities was lower than was expected.

Further pressures have been caused by lack of professional knowledge impacting on families. Parents attending ESIPP trainings have reported situations where they had previously been given information by professionals that was factually incorrect. Some professionals, for example, have advised parents that the use of images to support communication will impede speech development, though research evidence has shown that such approaches may aid such development (Ganz & Simpson, 2004) and that even where language does not emerge they can enhance communication (Flippin *et al.*, 2010). Challenging behaviour may be addressed by punitive approaches, rather than through positive behavioural support, though such interventions have been shown to be more effective for many years (LaVigna & Willis, 2012). In a region where there is a lack of understanding about ASD, parents are vulnerable to quasi-professionals offer a "cure" for the condition (at expensive

prices); and parents and professionals alike may favour e.g. pharmacological interventions rather than behavioural or cognitive approach, despite there being no such interventions that address the core features of ASD (Broadstock *et al.*, 2007). This highlights the need not only for parent education but for improved professional training, and activity is ongoing to seek funding to develop teacher education in ASD within this country and others in Central Europe and the Balkans.

Conclusion

Overall the ESIPP project delivered training in ASD to more than 330 Croatian, Cypriot and Macedonian parents. In addition, participating in the project as trainers has enabled 18 professionals from the three countries to refine and develop their skills, impacting on their own day-to-day practice as teachers, psychologists and therapists. We believe that this has been an important project, and hope that it will be a catalyst for further development to support Macedonian professionals, parents and individuals with ASD.

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