

## Accessing parental perspectives to inform the development of parent training in autism in south-eastern Europe

David Preece<sup>a</sup>, Loizos Symeou<sup>b</sup>, Jasmina Stošić<sup>c</sup>, Jasmina Troshanska<sup>d</sup>,  
Katerina Mavrou<sup>b</sup>, Eleni Theodorou<sup>b</sup> and Jasmina Frey Škrinjar<sup>c</sup>

<sup>a</sup>Centre for Education and Research, School of Education, University of Northampton, Northampton, UK;

<sup>b</sup>School of Arts and Education Sciences, European University Cyprus, Nicosia, Cyprus; <sup>c</sup>Faculty of Education and Rehabilitation Sciences, University of Zagreb, Zagreb, Croatia; <sup>d</sup>Macedonian Scientific Society for Autism, Skopje, Former Yugoslav Republic of Macedonia

### ABSTRACT

Parent training has been shown to be an important means of supporting families living with autism – but such services are not universally accessible. A multinational project funded by the European Commission has been developed in order to establish such parent training in three south-eastern European countries. To ensure that the training was relevant and appropriate, a survey was carried out in autumn 2015 to ascertain the attitudes of parents of children with autism in Croatia, Cyprus and the Former Yugoslav Republic of Macedonia regarding this issue, and to identify the areas of training that they felt most important. Two hundred and fifty-three surveys were distributed, and 148 were returned, a response rate of 58%. Respondents in the three counties were overwhelmingly positive about parent training, with almost 90% stating that they would like to attend such training. Weekend training sessions were preferred by the majority of respondents. There was wide variation between the three countries with regard to what content was felt important to be included, with parents in the FYR of Macedonia seeking information in the greatest number of areas. Five topics were prioritised by parents across all three countries. These were:

- Strategies for enhancing my child's communication
- Strategies on facilitating my child's interaction with other children
- Sensory integration and development
- General information on behavioural management strategies
- Identifying and/or developing socialisation opportunities

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## Introduction

Autism is a pervasive and lifelong developmental condition, characterised by differences and difficulties in social interaction and social communication, the ability to think and act flexibly and the perception and management of sensory stimuli (American Psychiatric

**CONTACT** David Preece  [david.preece@northampton.ac.uk](mailto:david.preece@northampton.ac.uk)

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Association 2013). The presence of autism in families is associated with elevated parental stress (Hayes and Watson 2013) and autism can negatively affect parental well-being and quality of life (Benjak 2011; Benjak, Vuletić Mavrinac, and Pavić Šimetin 2009; Mouzourou, Santos, and Gaffney 2011). The wider family may also be impacted, including siblings (Petalas et al. 2012), the wider family (Margetts, Le Couteur, and Croom 2006) and the individuals with autism themselves (McCabe, Hillier, and Shapiro 2013; Preece and Jordan 2010). Autism can challenge traditional parenting styles, making parents feel deskilled and disempowered, especially when little information or support is available to them (Dunn et al. 2001). Conversely, the provision of accurate information and training can increase family adaptation and acceptance, and improve personal, educational and social outcomes for individuals with autism and their families (Green et al. 2010; Kasari et al. 2010; Preece and Almond 2008). However, the literature suggests autism awareness is generally low within the Balkans and south-eastern Europe (Demirok and Baglama 2015; Stankova and Trajkovski 2010), and support for families (including parent education) is extremely limited or non-existent (Delfos 2010; Kulla and Gjedia 2015; Salomone et al. 2015). This is the case in the three participating countries: Croatia, Cyprus and the Former Yugoslav Republic of Macedonia.

To address this situation, a three year project has been established, funded by the European Commission's Erasmus+ programme. Professionals, academics and family members from across Europe are working to develop a core parent education curriculum and context-appropriate materials and methods; to provide and establish parent training for families living with autism in the three south-eastern European countries (evaluating its impact using quantitative and qualitative methods); and to share the curriculum and materials with stakeholders throughout Europe. Initial training sessions have been led by trainers from Cyprus and the United Kingdom, supported by local trainers in Croatia and the FYR of Macedonia. As the project develops, local trainers will lead the sessions without external support. This paper reports on an initial survey undertaken to identify the perspectives of families in the three participating countries regarding training.

## **Autism and education in Croatia, Cyprus and the FYR of Macedonia**

Diagnosis of autism is emergent in these countries, and information is limited regarding number of individuals with autism. In Cyprus and the FYR of Macedonia this number is not known. In Croatia, 1480 people are identified as having autism, 1036 of them below 18 years old (Benjak 2015). This indicates an identified prevalence of 4 per 10,000, far below the world-wide median prevalence estimate of 62 per 10,000 (Elsabbagh et al. 2012). Croatian partners suggest that prevalence is grossly underestimated. Factors contributing to this include incomplete data within the national register and diagnostic substitution (Coo et al. 2008; King and Bearman 2009), as many older individuals may be diagnosed with intellectual disability.

Despite international policy such as the Salamanca Statement (United Nations Educational, Scientific and Cultural Organization (UNESCO) 1994) and national legislation endorsing children's entitlement to education, inclusion of children with autism remains a nascent concept in these countries. Educational provision for these children, as elsewhere where inclusive education is developing (Department for International Development (DFID) 2010) is often restricted to segregated, specialist settings; and school staff's understanding of 'good autism practice' may be limited (Trnka and Skočić Mihić 2012), impacting upon the level of support available to parents.

Croatian legislation supporting the inclusion of children with special educational needs was passed in 1980 (Official Announcement Publications 1980). However, only 0.38% of children diagnosed with autism attend preschool, and even fewer (0.15%) are fully included in mainstream primary education (Sekušak-Galešev, Frey Škrinjar, and Masnjak 2015). Most school-aged children with autism are taught in special schools or special units within regular schools. There is no clear diagnostic pathway, and early intervention programmes are highly variable in availability and quality (Ombudsman for Children with Disabilities 2014).

In Cyprus, education for children with special needs has traditionally taken place in segregated special schools, though some children have 'unofficially' been integrated in mainstream schools for almost three decades (Symeonidou 2002). This action was legitimised by the Education Act for the Education of Children with Special Needs (Ministry of Education and Culture 1999). Despite this, however, children with autism are mainly educated in separate, often autism-specific, settings.

In the FYR of Macedonia, preschool services are required to accept children with autism; however, lack of expertise means that few do, and most preschoolers with autism remain at home. The Laws on Primary and Secondary Education (Ministry of Education and Science 1995a, 1995b) require 'suitable conditions' and 'individual assistance to be provided for learners with special educational needs. However, such conditions are seldom provided within mainstream schools. A 2014–2015 survey identified that only 67 of 256 primary schools included pupils with autism; of these only 14 had run seminars to provide staff with information about the condition (Ombudsman of the Republic of Macedonia 2015). Of 482 children with special educational needs included in mainstream education in Skopje, only 52 have autism (Ministry of Education and Science 2015). One third of the pupils in the country's four special schools have autism; others are taught in five special units attached to mainstream schools across the country, or are at home.

## Parent training and support

Project partners undertook a baseline audit in autumn 2015 to identify what training and support was available for parents of children with autism within these countries.

### Croatia

Croatia has a small number of specialist services providing support and training to such families. Non-governmental organisations (NGOs) provide early intervention programmes in some areas, and specialist institutions and NGOs may also provide parent and sibling support groups. A number of autism-specific parent organisations exist, and have organised specific training events about the Picture Exchange Communication System (PECS) (Frost and Bondy 2002), the Developmental, Individual-differences and Relationship-based model (DIRFloortime) (Wieder and Greenspan 2003), Applied Behaviour Analysis (ABA) (Simpson 2001) and sensory integration (Iarocci and McDonald 2006). Families with children with autism also participate in generic programmes for families with children with disabilities. Though there are many initiatives and activities in this area, there are also challenges. Support is often project-based, and unsustainable; much training is generic, rather than autism-specific; and provision is limited, and inaccessible for many families.

## Cyprus

Parent training about autism in Cyprus is very limited. One-day awareness seminars are provided by universities and the government. Some parent organisations provide services and hold occasional ad hoc seminars and conferences. Parent groups, often linked to schools, provide mutual support. NGOs and private initiatives are available to parents, providing training about assistive technologies and structured approaches such as PECS, ABA and TEACCH (Treatment and Education of Autistic and Communication-handicapped Children) (Mesibov, Shea, and Schopler 2005). Limited parent training informed by the UK National Autistic Society's EarlyBird programme (Shields 2001) has also been provided.

## FYR of Macedonia

The FYR of Macedonia has three young autism-specific parent organisations, providing information sessions and fund-raising events. A generic disability parent organisation has run a seminar on PECS and one on ABA. The Macedonian Scientific Society for Autism provides free lectures about autism and specific approaches, such as PECS, TEACCH and ReAttach therapy (Weerkamp-Bartholomeus 2015). However, events are on an ad hoc basis and are inaccessible to most families.

## Methodology

Before developing the parent education curriculum and materials, it was vital to ascertain parents' views regarding training, regarding both content and delivery. The literature identifies the need for cultural sensitivity and awareness in services for autism (Dyches et al. 2004; Perepa 2014; Wilder et al. 2004) and there seemed no reason to presume otherwise regarding this project. These three countries are ethnically, culturally and economically disparate. Therefore, a necessary initial activity of the partnership was to survey families living with autism there to develop a training curriculum and materials that were context-appropriate.

## Data collection tool and analysis

An anonymous structured questionnaire format was developed to identify parents' attitudes and opinions regarding both 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 training in autism (e.g. Bearss et al. 2013; Beaudoin, Sébire, and Couture 2014; Matson, Mahan, and Matson 2009; Roberts and Pickering 2010; Schultz, Schmidt, and Stichter 2011) and pre-existing training models (e.g. McConachie et al. 2005; Oosterling et al. 2010; Shields 2001). Twenty-seven training topic areas were identified, grouped within six domains as follows:

- Domain I: Awareness and general information
- Domain II: Communication
- Domain III: Specific approaches
- Domain IV: Self-care and behaviour
- Domain V: Socialisation and relationships
- Domain VI: Leisure and recreation

The draft questionnaire was translated into Croatian, Greek and Macedonian and piloted in each country. Amendments were made before the questionnaire was distributed (electronically and/or hard copy) in early November 2015. Ethical approval for the study and instrument was obtained by the partnership's lead institution (the University of Northampton). A covering letter identifying the purpose of the study accompanied the questionnaire. Consent was interpreted by response.

Questionnaires were sent to schools where there were known to be children with autism, NGOs in the field of autism, parent associations and support groups, for distribution to parents of children with autism known to them. Parents were requested to submit one response only. The partial nature of the sample and the potential for bias is acknowledged. However, given the dearth of accurate data regarding the number, prevalence and location of families living with autism, this sampling strategy was adopted as an effective way to contact such families in these countries.

In Croatia, 83 parents were surveyed with 44 responses (53% response rate): respondents came from locations including Zagreb ( $n = 28$ ), Rijeka ( $n = 9$ ), Zaprëšić ( $n = 1$ ), Zabok ( $n = 1$ ) and Sesvete ( $n = 1$ ). In Cyprus, 133 parents were surveyed with 66 responses (51% response rate): respondents came from the Famagusta ( $n = 14$ ), Limassol ( $n = 42$ ) and Nicosia ( $n = 10$ ) areas. Fifty families in the FYR of Macedonia were surveyed with 38 responses (76% response rate): respondents came from Skopje ( $n = 23$ ), Kavadarci ( $n = 5$ ), Gevgelija ( $n = 4$ ), Stip ( $n = 3$ ), Negotino ( $n = 1$ ), Prilep ( $n = 1$ ) and Tetovo ( $n = 1$ ). In total, 266 questionnaires were distributed and 148 returned, a response rate of 58%. The sample is drawn unequally from the three countries: 30% of respondents were Croatian ( $n = 44$ ), 45% were from Cyprus ( $n = 66$ ) and 25% were Macedonian ( $n = 38$ ). Data are presented both as numbers and percentages, regarding the whole data-set (*All respondents*) and by country. Data analysis was undertaken using SPSS and Excel.

### ***Respondents and their families***

The majority of respondents were aged 31–50 (see Table 1) with children aged 5–15 (see Table 2). The age range of children/young people was 1–24 years; over half were aged between 5 and 10 years. Mean age of children across the whole sample was 9.8 years ( $SD = 4.4$ ) – Croatia: 10.1 years ( $SD = 4.7$ ); Cyprus: 9.2 years ( $SD = 4.2$ ); FYR of Macedonia: 9.8 years ( $SD = 2.9$ ). In just under three quarters of cases, the respondent was the child's mother.

## **Findings**

### ***Parental interest in training***

Respondents exhibited high interest in parent training seminars and workshops, with almost 90% wishing to attend such events. Interest was lowest (75%) in Croatia, with 92% of Cypriot respondents expressing interest, and 97% in the FYR of Macedonia. Respondents also identified other family members that would be interested in participating in such training. Siblings were identified as potential participants by 25% of respondents, and grandparents by 10%. Desire for wider family involvement was stronger in Cyprus than the two Balkan nations.

**Table 1.** Age of respondents.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No.	%	No.	%	No.	%
Under 20	1	<1	0	0	0	0	1	3
21–30	7	5	1	2	3	5	3	8
31–40	59	40	18	41	26	39	15	39
41–50	68	45	21	48	28	42	19	50
Over 40	13	9	4	9	9	14	0	0

**Table 2.** Age of child/young persons with autism.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No.	%	No.	%	No.	%
Under 5	11	7	4	9	5	8	2	5
5–10	84	57	24	55	42	64	19	50
11–15	36	24	9	20	11	17	16	42
16–18	12	8	5	11	6	9	1	3
19 yrs+	5	3	2	5	2	3	0	0

### **Barriers to training**

Potential barriers to participation in training were identified. Parents' work schedules were a major consideration, affecting 55% of Macedonian parents, and almost 40% of respondents overall. Childcare issues affected a quarter of respondents overall (and over half the parents in Croatia). Only 10% of Croatian parents and 29% of Macedonian parents identified that they would have no difficulties attending training; by contrast, almost 60% of respondents in Cyprus identified no difficulty in attending. This may reflect cultural differences between Balkan and Cypriot settings regarding support available from grandparents and the extended family (Georgas et al. 2001).

### **How should training be carried out?**

Respondents overwhelmingly wanted training to take place in their own city or locality, to alleviate difficulties associated with childcare or work schedules. There was strong interest in weekend training: this was preferred by almost 60% of families. Regarding which time of day was best for attendance, no single approach was favoured by 50% of respondents across the whole sample. Half of Macedonian respondents expressed a preference for evening sessions, but this was not replicated elsewhere. This suggests that attempting to develop one single training process would be inappropriate, and that different delivery models may be required across the countries.

### **Content of the training programme**

As identified above, 27 topics in six domains were identified through the initial design process; two further topics were added as a result of responses. Findings are presented with reference to these domains.

**Table 3.** Potential training content: Domain I – Awareness and general information.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No.	%	No.	%	No.	%
General knowledge and information about autism	94	64	28	64	37	56	29	76
Policy, legislation and rights	91	61	31	70	25	38	35	92
Awareness and help in the community	78	53	32	73	19	29	27	71
Coping and emotional response to living with autism	70	47	19	43	31	47	20	53
Strategies to raise awareness in family and friends	69	47	19	43	29	44	21	55

**Table 4.** Variation in parents' interest in topics in Domain I between countries.

Topic	$\chi^2$	df	Significance level
Policy, legislation and rights	32.072	2	.000
Awareness and help in the community	27.354	2	.000

### ***Awareness and general information***

There was interest in general knowledge and information about autism across the sample, with about two-thirds identifying this as a requirement (see Table 3).  $\chi^2$  analysis (see Table 4) identified statistically significant differences between the three countries regarding two topics: policy, legislation and rights; and awareness and help in the community.

While only 38% of Cypriot respondents felt information concerning policy, legislation and rights should be included, this considered important by 70% of Croatian respondents, and 92% of Macedonian respondents. There may be greater awareness already within Cyprus; or social structures may be such that this is less of an issue, in that it is a small country with a centralised educational, health and social system, where policy actions are rapidly spread among interested stakeholders (such as parents and educators). Additionally, Cypriot legislation and policy regarding special education and inclusion have remained unchanged since 1999, despite the efforts of activists and academics to bring about reforms (Liasidou 2008; Symeonidou and Mavrou 2014). As a result, parents of children with autism in Cyprus may already be aware of them.

In Croatia it is identified that although legislation exists to support families with children on the autism spectrum and other disabilities, services are fragmented and the pathways to services and benefits are unclear (Benjak 2011; UNICEF 2014). Parents and professionals report that – from screening to diagnosis to accessing services – families often feel they have to ‘fight the system’.

Awareness and help in the community was also seen as less important for Cypriot families. Only 29% of Cypriot participants found that topic important, while it was viewed as important for 73% of Croatian and 71% of Macedonian participants.

### ***Communication***

Communication was a clear priority area for respondents; with 83% of parents identifying learning effective strategies for enhancing their child's communication as an area in which they desired training (see Table 5). There are statistically significant differences between

**Table 5.** Potential training content: Domain II – Communication.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No.	%	No.	%	No.	%
Strategies for enhancing my child's communication	123	83	39	89	55	83	32	84
Improving communication at home	108	73	20	45	63	95	25	66
'High tech' alternative communication (AAC)	85	57	26	59	30	45	29	76
'No & low tech alternative communication (AAC)	80	54	19	43	35	53	26	68

**Table 6.** Variation in parents' interest in topics in Domain II between countries.

Topic	$\chi^2$	df	Significance level
Improving communication at home	34.802	2	.000
'High tech' alternative communication (AAC)	9.465	2	.009

**Table 7.** Potential training content: Domain III – Specific approaches.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No.	%	No.	%	No.	%
Sensory integration and development	111	75	38	86	42	64	31	82
Structured approaches (e.g. ABA, PECS, TEACCH)	100	68	33	75	36	55	31	82
Interactional approaches (e.g. DIRFloortime)	3	2	1	2	0	0	2	5
Positive behavioural support	2	1	0	0	2	3	0	0

countries in the topics regarding improving communication at home and high tech alternative communication AAC (see Table 6).

Communication within the home was strongly prioritised in Cyprus, where 95% of respondents identified this as a training need. 'High tech' alternative communication was of more interest to Macedonian respondents (76%) than those from Croatia and Cyprus.

### *Specific approaches*

Parents were particularly interested in addressing their children's sensory issues and sensitivities, with 75% identifying sensory integration and development as important content for training (see Table 7). Over two-thirds of parents expressed a desire to learn about structured approaches (e.g. ABA, TEACCH, PECS). There are identified statistically significant differences regarding these topics between the countries (see Table 8).

Significantly fewer parents in Cyprus were interested in these topics than in the two Balkan nations. As identified above, private speech therapists or special educators provide training or services regarding structured approaches, and some respondents there may already be able to access such approaches. Few educators use such structured approaches in Croatia, which has led to parents and families having limited and/or poor experiences regarding them. This is an area that will be investigated further as the project continues.



**Table 8.** Variation in parents' interest in topics in Domain III between countries.

Topic	$\chi^2$	df	Significance level
Structured approaches (e.g. ABA, PECS, TEACCH)	9621	2	.008
Sensory integration and development	8.453	2	.015

### *Self-care and behaviour*

Behaviour management was a key issue for families across the three countries, with 73% of respondents expressing a need for information concerning behaviour management strategies, and 62% seeking information regarding the development of daily routines to address issues such as toileting and sleeping (see Table 9). There are statistically significant differences between countries regarding strategies on changing specific behaviours at home and in the community, managing aggressive and/or self-injurious behaviour, developing child's self-care skills and dealing with sexuality/adolescence (see Table 10).

Training regarding strategies to change specific behaviours was particularly important to Macedonian respondents (68%) but much less so within Cyprus (30%). It is unclear whether this is due to respondents' experiences or indicative of broader attitudes towards autism: this merits further study. Similarly, managing aggression and self-injurious behaviour was considered less important in Cyprus (where only 30% of respondents identified it as a need) than in Croatia or the FYR of Macedonia. The need to deal effectively with challenging behaviour has been raised by the Croatian Ombudsman for Children with Disabilities, which has called for improvements regarding assessment and intervention (Ombudsman for Children with Disabilities 2014).

Macedonian respondents were more interested than those elsewhere regarding strategies to develop children's self-care skills (63%) and to address issues relating to adolescence and sexuality (79%). This may relate to the age profile of respondents' children: 45% of Macedonian respondents had children aged 11 and over.

### *Socialisation and relationships*

As with communication, socialisation was viewed as important, with 83% of respondents seeking strategies to help their children interact with other children, and almost three-quarters seeking to identify and develop social opportunities (see Table 11). Statistically significant differences were identified between the three countries regarding the family's socialisation and social life and sexuality and/or relationships (see Table 12).

Croatian and Macedonian respondents identified interest in strategies to support the family's socialisation and social life; while significantly more participants in Macedonia were interested in issues on sexuality and relationships (see Table 12). It is unclear whether this results from respondents' children's ages and behaviours or is indicative of wider issues regarding family life in these countries, or attitudes towards disability and sexuality (Buljevac, Majdak, and Leutar 2012; Phiatka 1999). This will also be further investigated as the project progresses.

Table 9. Potential training content: Domain IV – Self-care and behaviour.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No	%	No.	%	No	%
General information on behavioural management strategies	108	73	33	75	49	74	26	68
Strategies on working on daily routines (toilet, sleep, etc.)	92	62	23	52	40	61	29	76
Structuring home environment to support skills development and behaviour	75	51	15	36	37	56	23	61
Strategies on changing specific behaviours at home and in the community	68	46	22	50	20	30	26	68
Strategies on managing aggressive and/or self-injurious behaviour	65	44	25	57	20	30	20	53
Strategies on developing child's self-care skills	62	42	18	41	20	30	24	63
Strategies on dealing with sexuality and relevant adolescence issues	60	41	21	48	9	14	30	79

**Table 10.** Variation in parents' interest in topics in Domain IV between countries.

Topic	$\chi^2$	df	Significance level
Strategies on developing child's self-care skills	10.719	2	.005
Strategies on managing aggressive and/or self-injurious behaviour	9.111	2	.011
Strategies on changing specific behaviours at home and in the community	14.523	2	.001
Strategies on dealing with sexuality and relevant adolescence issues	44.015	2	.000

**Table 11.** Potential training content: Domain V – Socialisation and relationships.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No.	%	No.	%	No.	%
Strategies on facilitating my child's interaction with other children	123	83	33	75	55	83	35	92
Identifying and/or developing socialisation opportunities	107	72	34	77	42	64	31	82
Issues on family's socialisation and social life	86	58	27	61	31	41	28	74
Strategies on facilitating my child's interaction with other family members	81	55	18	41	40	61	23	61
Issues of sexuality and/or relationships	53	36	14	32	14	21	25	66
Going to doctors/dentist	1	<1	1	2	0	0	0	0

**Table 12.** Variation in parents' interest in topics in Domain V between countries.

Topic	$\chi^2$	df	Significance level
Issues on family's socialisation and social life	7.343	2	.025
Issues of sexuality and/or relationships	21.281	2	.000

### **Leisure and recreation**

Leisure and recreation issues were given a comparatively low priority overall (see Table 13). There are statistically significant differences between the countries in all topics in this domain (see Table 14). Again overall percentages are affected strongly by the figures from Cyprus, where 72% of the respondents' children were under-10, and where e.g. grandparental involvement seems higher than in the other two countries.

In the FYR of Macedonia, 45% of respondents' children were 11 years or older (compared with 36% in Croatia and 29% in Cyprus). Developing strategies to help the child with autism engage with others in leisure activities was identified as a priority by 92% of Macedonian respondents, and developing leisure activities for the child in general was prioritised by 87%. It may be that training in these areas will be more important for families with older children.

### **Discussion**

It is self-evident that parents were most likely to respond to this survey if they were interested in training, and the results must be interpreted in this light. Nonetheless, both the overall response rate (58%) and the number of families wishing to attend and participate in training (89%) suggest that providing parent training in autism would be of interest to many families. This is valuable information, confirming the activity of this strategic partnership to be

**Table 13.** Potential training content: Domain VI – Leisure and recreation.

	All respondents		Croatia		Cyprus		FYR of Macedonia	
	No.	%	No.	%	No.	%	No.	%
Developing strategies to engage the child with other children and people in leisure activities	97	66	28	63	34	51	35	92
Identifying and developing leisure activities for child	96	65	34	77	29	44	33	87
Structuring the home environment for safe and interesting leisure activities	64	43	21	48	21	32	22	63

**Table 14.** Variation in parents' interest in topics in Domain VI between countries.

Topic	$\chi^2$	df	Significance level
Identify and develop leisure activities for my child	23.706	2	.000
Structure home environment for safe and interesting leisure activities	7.194	2	.027
Strategies for engaging my child with other children and people in leisure activities	15.288	2	.000

worthwhile. Furthermore, the survey has also identified that content which respondents consider most important to be included in parent training programmes.

There is at times wide variation between the responses of the three sets of parents regarding training priorities, with statistically significant differences between countries in 13 topic areas across all 6 domains. This supports the project's initial premise: that no single training model or curriculum would be appropriate across the three countries, and that consideration must be given to bespoke content and bespoke delivery methods. Therefore, the partnership agreed to prioritise training in areas where > 60% of respondents indicated interest. Eight such areas (28% of all potential topics) were identified with regard to Cyprus, compared to 12 for Croatia (41%), and 21 for the FYR of Macedonia (72%). This may reflect parental engagement with and knowledge about therapeutic approaches and services: these are more developed within Cyprus and Croatia than the FYR of Macedonia. As part of the evaluation of the parent training (which commenced in March 2016), the team will investigate this and other issues highlighted by the survey.

Five topics were identified as areas of interest for training by > 60% of respondents across all three countries. These were:

- Strategies for enhancing my child's communication (*Domain II*)
- Strategies on facilitating my child's interaction with other children (*Domain V*)
- Sensory integration and development (*Domain III*)
- General information on behavioural management strategies (*Domain IV*)
- Identifying and/or developing socialisation opportunities (*Domain V*)

Therefore, initial planning regarding training content focused upon these topics (whilst of course paying heed to and seeking to address the other topics prioritised within individual countries).

These five topics address difficulties regarding communication, socialisation, sensory issues and behaviour. These are core difficulties in autism, and it is unsurprising they were identified as important by respondents. These topics are considered key in parent training (Patterson, Smith, and Mirenda 2011; Schultz, Schmidt, and Stichter 2011); and interventions focusing on communication, playing with peers and positive, proactive approaches to problem behaviour are identified by the National Research Council (2001) as educational priorities for children with autism. Furthermore, numerous studies identify that problem behaviours are a major stressor for parents of children with (Glazzard and Overall 2012; Hall and Graff 2011; Nealy et al. 2012; Weiss and Lunskey 2011) so it is unsurprising this is prioritised. It seems reasonable to conclude that parents in these three countries – as elsewhere – feel the need for support with these key issues.

Research also highlights that stigma, due to the child with autism's difference from others, is often experienced by families living with autism (Farrugia 2009; Gray 2002); and helping the child with autism to understand and interact more adaptively with 'mainstream society' is a goal of many programmes and interventions (Barry and Burlew 2004; Rao, Beidel, and Murray 2008). Effective training in these five core topics may not only help parents accept and understand how their children experience the world, but may support them in helping their child be included in wider society. This is of particular concern in south-east Europe, as research indicates societal prejudice is still prevalent concerning disability. Negative attitudes, stereotyping and prejudice have been identified in all three countries (Buljevac, Majdak, and Leutar 2012; Kostikj-Ivanovikj 2015; Theodorou and Mavrou 2014) and parents and educators in Cyprus consider such prejudice defines attitudes towards children with disabilities even in educational settings (Damianidou and Phtiaka 2013).

In addition to the autism-specific content, this study identified parental interest – particularly in Croatia and the FYR of Macedonia – regarding information about policy, legislation and rights. This is important, and local trainers will develop training materials and information (in conjunction with service providers and other professionals within their countries) to address this in separate training sessions.

With regard to the training process, though the study did not identify consensus regarding parents' preferences, a majority of respondents across all three countries favoured training sessions at the weekends. As a result, a two-day training model has been developed, focused on the five core topics. The intention is that, when delivered by local trainers (without translation), this will be deliverable within a weekend.

The project will be evaluated using a mixed methods evaluation methodology incorporating questionnaires, interviews and reflective diaries. Data will be collected to investigate parental attitudes and experience, family quality of life and the impact of training. The curriculum, training materials and methodology will be further refined and developed in the light of the analysis of this data.

## Conclusions

As identified above, the survey respondents cannot be assumed to be representative, and therefore generalisation to the wider population of families living with autism in the three countries is not possible. Nonetheless, this survey has identified certain clear patterns among respondents which we believe are important to take into account in developing parent training. First and foremost is the significant interest in and demand from respondents in

these countries for training in autism. This may be seen as a response to the paucity of support structures and information about autism noted in the literature and initial audit concerning all three countries (e.g. Mavrou 2011; Mouzourou, Santos, and Gaffney 2011). Furthermore, the survey has identified a common core of topics considered important by respondents across all three countries; as well as highlighting differing priorities between the three countries, which initial investigation suggests may be understood in terms of differing availability of services, availability of support and societal structures between the three countries. Even within cultures, families adjust to living with autism in different ways (Gray 2001; Ryan and Runswick-Cole 2009), and no single approach can ever be appropriate for all. Nonetheless, we would argue that this study validates both the purpose and the proposed methodology of this project – to develop training models and content relevant to each area; and we look forward to reporting on its progress as the project continues.

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## Notes on contributors

*David Preece* is a senior lecturer in the Centre for Research and Education at the University of Northampton. His research interests include social support for families living with autism and other disabilities, social attitudes towards disability and inclusion.

*Loizos Symeou* is an associate professor in the Sociology of Education at the European University Cyprus, and Dean of the School of Arts and Education Sciences. His areas of interest are in the sociological investigation of school–parent–child relationships and how these link to family cultural and social capital.

*Jasmina Stošić* works as a teacher and researcher in the Faculty of Education and Rehabilitation Sciences, University of Zagreb. She also undertakes clinical work, focused on providing assessment and support for children with ASD and their families. Her research interests include the use of ICT tools for teaching children with disabilities, and using robots in the diagnostic assessment.

*Jasmina Troshanska* is Vice-President of the Macedonian Scientific Society for Autism, as well as being a special education teacher teaching children with intellectual disabilities. She is currently completing her doctorate at the University of SS Cyril & Methodius, Skopje, where she is researching sensory issues in children with autism.

*Katerina Mavrou* is an assistant professor in Inclusive Education and Assistive Technology at the European University Cyprus. Her areas of interest are in the use Information and Communication Technology and Assistive Technology (ICT-AT) in inclusive education, learning and everyday life of children with disabilities, universal design for learning and the involvement of end users and families.

*Eleni Theodorou* is an assistant professor at the European University Cyprus. Her main research interests include sociological and anthropological constructions of childhood, intercultural education policy and politics, family–school relations and sociological understandings of teacher professional identities.

**Jasmina Frey Škrinjar** is Head of the Department for Autism Spectrum Disorders in the clinical unit of the Faculty of Education and Rehabilitation Sciences. Her areas of her research and professional interests are persons with severe intellectual disabilities, mental health and behavioural disorders, and persons on the autism spectrum disorders.

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