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Title: Being part of it: a partnership for developing evidence-based parent education in autism in south-eastern Europe

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Example citation: Preece, D., Symeou, L., Mavrou, K., Stošić, J. and Troshanska, J. (2016) Being part of it: a partnership for developing evidence-based parent education in autism in south-eastern Europe. Paper presented to: *European Conference on Educational Research (ECER) 2016, Dublin, 23-26 August 2016*.

Version: Presented version

<http://nectar.northampton.ac.uk/8710/>





Co-funded by the
Erasmus+ Programme
of the European Union



ESIPP

EQUITY AND SOCIAL INCLUSION THROUGH
POSITIVE PARENTING

Being Part Of It: A Partnership For Developing Evidence-based Parent Education in Autism in south-eastern Europe

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ECER Conference, 23-26 August 2016, Dublin, Ireland



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Autism

- Pervasive and lifelong developmental condition (American Psychiatric Association, 2013)
- Associated with elevated parental stress (Hayes & Watson 2013)
- Can negatively affect parental well-being and quality of life (Benjak 2011; Benjak, Mavrinac & Šimetin 2009; Mouzourou, Milagros & Gaffney 2011)
- Other family members may also be impacted:
 - siblings (Petalas *et al.* 2012)
 - wider family (Margetts *et al.* 2006)
 - individuals with autism themselves (McCabe *et al.* 2013; Preece & Jordan 2010).

Benefits of information about autism

- Autism challenges traditional parenting styles:
 - can make parents feel deskilled and disempowered, especially when little information or support is available to them (Dunn *et al.* 2001)
- Provision of accurate information and training:
 - can increase family adaptation and acceptance/improve personal, educational and social outcomes for individuals with autism and their families (Preece & Almond 2008; Green *et al.* 2010; Kasari *et al.* 2010)
- Autism awareness:
 - generally low within Balkans and SE Europe (Demirok & Baglama 2015; Stankova & Trajkovski 2010)
 - support for families extremely limited or non-existent (Delfos 2010; Kulla & Gjedia 2015; Salomone *et al.* 2015).

Equity and Social Inclusion through Positive Parenting (ESIPP)

- Three year project
- Funded by the European Commission's Erasmus+ programme.
- Professionals, academics and family members from across Europe working to:
 - develop a core parent education curriculum and context-appropriate materials and methods
 - provide and establish parent training for families living with autism in Croatia, Cyprus and the Former Yugoslav Republic of Macedonia (evaluating its impact using quantitative and qualitative methods)
 - share the curriculum and materials with stakeholders throughout Europe

The training

- 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.
- To date 60+ parents have received 'core' training.



What are we reporting on here today?

- Our paper reports on an initial survey undertaken to identify the perspectives of families in the three participating countries regarding training
- Before developing the parent education curriculum and materials, we felt it was vital to ascertain parents' views regarding training, regarding both content and delivery
- Reflects the need for cultural sensitivity and awareness in services for autism (Dyches *et al.* 2004; Perepa 2014; Wilder *et al.* 2004)

Data collection tool (I)

- Anonymous structured questionnaire to identify parents' attitudes and opinions regarding both delivery of parent training (timing, length of sessions, potential barriers) and training content
- Questionnaire design informed by review of the literature regarding:
 - parent training in autism (e.g. Bearss *et al.* 2013; Beaudoin, Sébire & Couture 2014; Matson, Mahan & Matson 2009; Roberts & Pickering 2010; Schultz, Schmidt & Stichter 2011)
 - pre-existing training models (e.g. McConachie *et al.* 2005; Oosterling *et al.* 2013; Shields 2001)

Data collection tool (II)

- Twenty-seven training topic areas grouped within six domains:
 - *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
- Piloted in all 3 countries then distributed (electronically and/or hard copy) in autumn 2015.
- Ethical approval obtained by the partnership's lead institution (the University of Northampton).

Sample

- Croatia: 83 families were surveyed with 44 responses (53% response rate)
- Cyprus: 133 families-66 responses (51% response rate)
- FYR of Macedonia: 50 families-38 responses (76% response rate)
- Overall response rate: 266 families surveyed-148 responses (58% response rate)

Demographic characteristics of the sample

- The majority of respondents were aged 31-50 with children aged 5-15
- 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.

Main findings (I)

- Overall response rate (58%) and the number of families wishing to attend and participate in training (89%) suggests that providing parent training in autism would be of interest to many families
- **But...**
- Wide variation between the responses of the three sets of parents regarding training priorities, with statistically significant differences between countries in 13/27 topic areas across all six domains

Our main findings (II)

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

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 socialization opportunities

Main findings (III)



- Identified parental interest – particularly in Croatia and the FYR of Macedonia – regarding information about policy, legislation and rights
- No consensus regarding parents' preferences on the training process, but majority of respondents across all three countries favoured training sessions at the weekends.

Discussion-Conclusions (I)

- The survey identified certain clear patterns among respondents to take into account in developing parent training:
 - significant interest in and demand from respondents in these countries for training in autism
 - 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, Milagros and Gaffney 2011)
 - confirms the activity of this strategic partnership to be worthwhile

Discussion-Conclusions (II)

- It identified content which respondents consider most important to be included in parent training programmes
- Common core of topics considered important by respondents across all three countries
- Differing priorities between the three countries were highlighted:
 - may be understood in terms of differing availability of services, availability of support and societal structures in the three countries;
 - supports the project's initial premise – no single training model or curriculum appropriate across the three countries

Discussion-Conclusions (III)

- Therefore, partnership agreed to prioritize training in 5 areas where >60% of respondents indicated interest
 - While also offering locally prioritized training where appropriate
- Evaluation of the parent training
 - Questionnaires, semi-structured interviews with parents
 - Focus groups and reflective diaries (trainers)
 - Will evaluate process and content of training, including all issues identified in the initial survey

Disclaimer

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