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

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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 (ESIPPP)

• 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
• 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
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