

Helping parents to understand and support their children with autism through parent education in south east Europe: the 'ESIPP' project

David Preece PhD

Centre for Education and Research, Faculty of Education and Humanities, University of Northampton, UK.

Abstract

Autism is a lifelong condition which can have a significant impact not only upon the individual with autism, but also on parents, siblings and the wider family. Parent education has been shown to be an important source of social support to families, helping them adjust to the reality of living with autism, and improving outcomes and quality of life for family members. However, such provision is not universally available, and nor may existing models of parent education be universally appropriate. This paper discusses the activity undertaken to date (November 2016) in the Equity and Social Inclusion through Positive Parenting (ESIPP) project. This is a partnership of academics, professionals and parents, funded by the European Union, working to develop and evaluate the impact of providing such training in Croatia, Cyprus and the Former Yugoslav Republic (FYR) of Macedonia. The paper reviews the literature regarding parent education, highlighting key benefits and barriers. It then moves on to introduce the ESIPP project, outlining key aspects of the project – the identification of the core curriculum, the parent education courses and the evaluation process – and summarising what we have learned in developing and providing parent education across cultures.

What is autism?

Autism is a lifelong developmental condition, characterised by differences and difficulties in social interaction, social communication, the ability to think and act flexibly and the perception and management of sensory stimuli. The condition has a worldwide median prevalence of 62 per 10,000 (Elsabbagh *et al.*, 2012), though this varies widely from region to region. In areas where diagnostic services and research into autism are well established, such as the UK, this figure can rise to about 1 per 100 (Baird *et al.*, 2006). In South America, only a handful of prevalence studies have been undertaken; within Brazil, a 2011 study undertaken in Atibaia (São Paulo State) identified a prevalence of just over 27 per 10,000 (Paula *et al.*, 2011). This would suggest either that prevalence within Brazil is very low, or that identification is only partial.

Impact of autism on the family

There is overwhelming and long-established evidence that the presence of autism can significantly affect families, causing greater parental stress than other disabilities (Wolf *et al.*, 1989) and impacting not only on the parents but on siblings (Petalas *et al.*, 2012), the wider family (Margetts *et al.*, 2006) and the individuals with autism themselves (Preece and Jordan, 2010). Families may be faced with a wide range of challenges and stressors, affecting the child's development and family functioning, cohesion and quality of life. Problems may be caused by the child's cognitive difficulties (Bebko *et al.*, 1987); their linguistic impairments (Gray, 1994); difficulties in sleeping (Hoffman *et al.*, 2008), eating (Ausderau and Juarez 2013; Martins *et al.*, 2008), personal care (Tomakin *et al.*, 2004), sexual expression (Gray, 2002) and behaviour (Chiang, 2008). Their need for sameness and routine can restrict the ability of families to undertake typical activities of daily life, such as shopping, eating out or getting a haircut (Vaughn *et al.*, 2002).

The presence of special educational needs and/or disability in the family can challenge parental expectations and preconceptions regarding family life and parenting (Seligman and Darling, 2009). These challenges may increase in the presence of autism. Due to the typical differences and difficulties in autism, parents' natural parenting styles and skills may well prove ineffective, as may approaches suggested for typically developing youngsters (Waltz, 1999). The 'hidden' nature of autism can lead others – both outside and inside the family – to make judgmental assumptions about parents and child alike, viewing the child as 'naughty' and parents as 'inadequate' (Preece, 2014). This experience of stigma can further reduce feelings of parental competence and self-efficacy (Dunn *et al.*, 2001) and can lead families to withdraw from social contact and experience significant levels of isolation (Woodgate *et al.*, 2008). The levels of stress, isolation and stigma that families experience are subject to a range of variables that can variously act as mediators and moderators. These include housing (Langworthy-Lam *et al.*, 2004), family finances and employment status (Cidav *et al.*, 2012), the child and family's experience of and relationship with school (Whitaker, 2007), and the availability of support, both informal and formal.

Supporting parents living with autism

The availability of informal social support – for example, from family, friends and neighbours – has been shown to be of great benefit to families living with autism (Ekas *et al.*, 2010), as

has the availability of and access to professional or formal' support services (Tarleton and Macaulay, 2002). Research has shown that families of children with autism receive more limited levels of informal social support than other families (Preece and Jordan, 2007). Therefore, the provision of appropriate, effective and accessible professional support – from educators, health professionals and workers in the field of social care – is of particular importance to these families. Interventions – including parent education – have been shown also to have an economic impact, reducing long term dependency and allowing the wider family to take a productive part in society (Buescher *et al.*, 2014).

Training and education for parents living with autism

Parent training and education are crucial aspects of the spectrum of support for families living with autism. There are a number of unsubstantiated – and sometimes dangerous – approaches being promoted on the internet, and parents are often unable to discriminate between what may be helpful and what can be harmful. Providing families with accurate information and training in effective approaches has been shown to increase family adaptation and acceptance, and improve personal, educational and social outcomes for individuals with autism and their families (Kasari *et al.*, 2010). There is a wide (and developing) literature focusing on parent training and education in autism. A large part of this literature focuses on training in specific intervention programmes such as Applied Behaviour Analysis (ABA) (Ingersoll and Dvortcsak 2006), structured teaching (Turner-Brown *et al.*, 2016). Other aspects of this literature deal with:

- more general and eclectic parent education models (e.g. McConachie *et al.*, 2005; Oosterling *et al.*, 2013)
- delivery process issues such as providing training to families in remote areas (Heitzman-Powell *et al.*, 2012) or online teaching (Vismara *et al.*, 2013)
- parent education in specific geographical settings, such as China (Wang 2008) or with specific ethnic groups such as Africans in the UK (Munroe *et al.*, 2016)
- parent training regarding specific issues (Kroeger and Sorensen 2010)
- providing an overview of parent training and education in this field (Schultz *et al.*, 2011).

Issues regarding parent training and education in autism

Research clearly and consistently identifies that educating parents about autism is valued (Whitaker, 2002), that it reduces parental stress (Brookman-Frazee & Koegel, 2004) and that its benefits may be maintained over time (Koegel *et al.*, 2002). Nonetheless, numerous problems and barriers have also been identified regarding such provision. These include difficulties maintaining regular attendance due to work or child care commitments, waiting times, access issues, distance and parental discomfort due to lack of ‘fit’ or intrusiveness (Birkin *et al.*, 2008). Moreover, though parent education programmes have been developed in a number of Western countries – and increasingly elsewhere - there are many areas of the world where there is little or no availability of such programmes or training materials. At the same time, autism may be conceptualised differently across different cultures (Kim, 2012; Perepa 2014): as a result, attempts to ‘transplant’ training models to different settings can be problematic, due to cultural, societal and systemic differences between countries and populations.

The ESIPP project

Both the literature and practitioner report suggest that the level of knowledge and understanding of autism is generally low within the region of the Balkans and south-eastern Europe (Demirok and Baglama 2015; Stankova and Trajkovski 2010). Diagnosis is emerging in this area, and services and support for families (including parent education) are extremely limited or non-existent (Salomone *et al.*, 2015). Recent studies have identified the importance of addressing the needs of families (Nolcheva and Trajkovski 2015). To address this situation, a three-year project – running from September 2015 to August 2018 – has been established, funded by the European Commission’s Erasmus+ programme. Academics, practitioners and family members from five European countries are working together in a strategic partnership, with the task of:

- developing a core curriculum and locally appropriate training materials and methods
- providing parent education to families living with autism in three south-eastern European countries: Croatia, Cyprus and the FYR of Macedonia
- evaluating the impact of the project using quantitative and qualitative methods
- sharing the curriculum and materials with stakeholders, and making recommendations to policy makers at local and national levels.

Identification of the parent training curriculum

Before commencing the development of the parent education curriculum and materials, it was important to identify the views of Croatian, Cypriot and Macedonian parents of children on the autism spectrum about parent education (with regard to curriculum and content as well as delivery). A review of the literature concerning parent education identified six key domains of training. These were:

- General awareness and information
- Communication
- Specific approaches
- Behaviour and self-care skills
- Socialisation and relationships
- Leisure and recreation

A structured questionnaire, informed by this literature review, was developed by the academic partners within the project. This was distributed to parents and family members in the 3 countries known to the project partners during autumn 2015. In total, 253 questionnaires were distributed and 148 were returned, a response rate of 58%. Response rate was 53% from Croatia (n=44), 51% from Cyprus (n=66) and 76% from the Macedonian families (n=38).

Parent education process

The results of this survey (Preece *et al.*, 2017) have been important in establishing both the process and content of the parent education curriculum, materials and programme. Respondents exhibited high interest in parent education seminars and workshops, with almost 90% wishing to attend such events. Respondents also identified that other family members would be interested in participating in such programmes, such as siblings (25%) and grandparents (10%). Desire for wider family involvement was stronger in Cyprus than the two Balkan nations.

A number of potential barriers to participation were identified. Work responsibilities were a major consideration, affecting almost 40% of respondents overall. Child care issues affected a quarter of respondents overall. Only 10% of Croatian parents and 29% of Macedonian parents identified that they would have no difficulties attending sessions; 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). Respondents overwhelmingly wanted programmes to take place in their own city or locality, to alleviate difficulties associated with child care or work schedules. There was strong interest in weekend workshops: this was preferred by almost 60% of families. Regarding which time of day was most suitable, no single approach was favoured by 50% of respondents across the whole sample. This clearly suggests that attempting to develop a single parent education process would be inappropriate, and that different delivery models may be required across the countries.

Training content

There was frequent wide variation between the responses of the parents in the three countries regarding their priorities: statistically significant differences between countries were identified in 13 out of the total of 29 topic areas across all six domains. This supported the project's initial premise: that no one model or curriculum would be appropriate across the three countries, and that consideration should be given to differentiated content and differentiated delivery methods. Development of materials was prioritised in areas where >60% of respondents indicated interest. Eight such areas were identified with regard to Cyprus, 12 for Croatia, and 21 for the Macedonian respondents. This may reflect the existing level of parental engagement with and knowledge about approaches and services, which are more developed in Cyprus and Croatia.

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

- Strategies for enhancing the child's communication (83%)
- Strategies on facilitating the child's interaction with other children (83%)
- Sensory integration and development (75%)
- General information on behavioural management strategies (73%)
- Identifying and/or developing socialization opportunities (72%)

These topics comprised the project's core curriculum, and initial planning regarding the curriculum and training materials focused upon these topics (whilst of course paying heed to and seeking to address the other topics prioritised within individual countries). They address core difficulties in autism, and it is unsurprising they were identified as important by respondents. The final curriculum will comprise:

- a core curriculum (differentiated as appropriate to the local setting)
- additional modules (developed to respond to local needs and preferences)

The parent education courses

Three courses have taken place during spring 2016. All courses were fully subscribed (approximately 20 parents per course), and were held during the day at the weekend as this was survey respondents' preference. More extended courses (including e.g. local-prioritised topics and 'tutorial' sessions) are taking place in autumn 2016. In total five courses will take place in each country. It is vital to the sustainability of the parent education programmes that they can eventually run without external trainer support. Therefore, partners have worked on the development of a 'Training the Trainer' package alongside the development of the parent training materials. This is being used to support the selection, development and validation of local trainers.

Evaluation of the parent education programme

The project is being evaluated using a combined process and outcome evaluation methodology (Royse *et al.*, 2009). This includes the use of quantitative and qualitative methods. Data is being collected in the following ways:

- **Participants.** All participants are asked to complete pre-training, post-training and follow-up questionnaires; Family Quality of Life scale, the CarerQoL (Hoefman *et al.*, 2014) has been integrated into these questionnaires. Four or five family members per cohort (identified via a purposive sampling strategy) are interviewed three months after the end of the training course. The interviews focus on participants' understanding of autism, their experience of autism in their daily life, their experience of the training and the impact (if any) of the training.
- **The training team.** Focus groups of the whole local training team in each of the three countries will take place once, at the end of the project. Questions on the focus group protocol collect data regarding the trainers' experience of being a trainer, their thoughts about the content and process of the courses, their perceptions regarding the effectiveness of the training and its impact and issues regarding differentiation of the model (e.g. with regard to materials, training process and style, training team issues). Reflective diaries are also being completed by all trainers.

- **Document analysis.** Documentary analysis will be undertaken of course evaluation data, the parent curriculum and training materials and other documents from the project. This will provide information regarding the development of the parent education curriculum and materials; participant feedback regarding the training content and process; barriers identified and addressed (and other programme process issues) and differentiation of materials (e.g. between countries, different groupings of participants)

What have we learned so far?

We are currently just over a year into our three-year project, and there is still much work to be done. Important future activity includes

- continuing to carry out the parent education programmes
- presenting the curriculum and materials to the wider community of stakeholders via local conferences and the website (www.esipp.eu)
- refining the curriculum and materials in response to feedback
- developing guidelines regarding parent education to present to local and national policymakers.

Nevertheless, we have learned a number of important points, both about the topic of parent education and the process of working together as a multi-national partnership.

With regard to parent education, it is clear that there is high interest in the topic, but equally clear that there are many barriers to successfully providing it, and that such education – content and process – must be appropriately locally differentiated. Models of family-professional relationships can differ between countries, and the level of parental involvement with professionals can range from very distant to very close. The parent education courses are delivered using a range of approaches, including lecture format, group discussions, interactive activities and one-to-one consultation. However, approaches that are appropriate and helpful in one setting can be inappropriate elsewhere. For example, parents who are used to interacting passively with professionals, and who are used to relating to professionals as experts, may feel uncomfortable when asked to participate and contribute actively within the sessions. As one parent unhappily stated, *‘I felt like I was taking an exam.’* Local trainers’ perceptions and understandings are vital to ensure that the trainings are suitable for the setting.

In terms of process, there are inevitable issues in working as a multi-national team of academics, practitioners and parents. Initially, different partners had differing priorities, perspectives and understandings about the project. Ensuring that all partners had a common, shared understanding, and matching partners' priorities with the expectation of the organisation funding the research took time and effort. Working in English as the project language will inevitably privilege the perspective of native English speakers, and it has been necessary to build in safeguards to ensure that all partners feel fully included and valued. This has meant working at a slower pace than some native English speakers initially felt comfortable with, which caused some frustration early on in the project. Also, some non-native speakers may believe that their English language skills are better than they actually are; this can cause them to become unhappy when it is identified that they have misunderstood something. A project culture has been established where frequent and repeated clarification of key points is the norm. This has helped to reduce misunderstanding and ensure that all partners feel included.

Projects do not exist in a vacuum, and cultural, political and historic tensions can and will impact at times. This has been the case within this project where, for example, issues have arisen due to the 'Macedonian naming dispute'. The country is recognised by the European Union, the project's funder, as the Former Yugoslav Republic of Macedonia. However, this name is considered pejorative by natives of the country. Such issues need to be dealt with openly, honestly and realistically, and a shared focus must be maintained regarding the purpose of the project and on ensuring outcomes are achieved.

Trainers need to be sensitive to local and cultural issues, and differentiate the training content and process appropriately. It is vital that external trainers spend time in local schools and homes to observe practice and develop an understanding of the local setting. Parent education needs to focus on principles, not equipment, and it is important to be realistic about resources, rather than having false expectations. The role of translators and local trainers is crucial, and it has become clear to us that the parent education content is being co-created by the entire team.

Finally, we have importantly learned that the similarities of families' experiences are greater than the differences between them. Families in all three countries are facing similar difficulties, share similar frustrations and experience similar joys. Parent education can be an important tool to support such families, and we look forward to continuing to learn alongside these families.

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