

Impact case study (REF3)

Institution: University of Northampton		
Unit of Assessment: 23 Education		
Title of case study: Revolutionising parents' and professionals' understanding and skills regarding autism in south east Europe		
Period when the underpinning research was undertaken: 2015 – 2018		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): David Preece	Role(s) (e.g. job title): Associate Professor	Period(s) employed by submitting HEI: 2015 - 2020
Period when the claimed impact occurred: 2015 -2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

Associate Professor David **Preece** led a 3-year, Erasmus+ KA2 Strategic Partnership in Adult Education: Equity and Social Inclusion through Positive Parenting (ESIPP) (2015-18). This innovative project developed and introduced locally-accessible education in autism for parents of children with autism in south-eastern Europe. During the project, 335 parents attended Autism Spectrum Disorder Empowering and Support Teachers (ASD-EAST) workshops and reported increased parental skills, understanding, confidence and happiness. Professional training has also been significantly enhanced. Since 2018, over 2,700 further parents, professionals and students in the region have received training. The project has led to enduring change in Croatia, Cyprus and North Macedonia, building capacity and ensuring ongoing sustainability.

2. Underpinning research

The University of Northampton's Centre for Education has a strong body of research in social/educational inclusion and disability. Associate Professor David **Preece** led ESIPP, a 3-year, Erasmus+ KA2 Strategic Partnership in Adult Education, bringing accessible, relevant parent education to families of children on the autism spectrum in Croatia, Cyprus and North Macedonia. Project partners were drawn from these countries, Belgium and the UK, including universities, schools, private enterprises and non-governmental organisations; impact identification measures were built into the methodology [3.1].

An initial literature review [3.2] identified benefits of parent education to individuals on the spectrum and their families. Exploratory research [3.3] in south east Europe demonstrated that such education – and appropriate support in general – was severely limited or non-existent. Knowledge about autism is emergent among professionals and the public, services and accessible materials in local languages are scarce, and families experienced high levels of stress and social exclusion [3.3, 3.4, 3.5]. A further survey of parents [3.3] showed high interest among families regarding parent education and also key areas of need for information and practical strategies. The core curriculum and materials were developed to specifically address topics identified as important by >60% of all respondents. Topics prioritised within specific countries were foregrounded within local training materials; and local training teams further developed materials relating to local policy, legislation and parental rights. Materials were based upon current 'best practice' in autism (the partnership included academics and trainers skilled in this area) [3.3].

As part of the research, and with content, process and delivery methodology directly informed by the exploratory study, the team created a parent education curriculum and accessible training materials, translated into Croatian, Greek and Macedonian [3.6]. Materials were locally adapted

Impact case study (REF3)

to the particular needs of each community as identified by the researchers, and the content of the curriculum and training reflected current accepted best practice in autism.

Trainers in the three countries were trained (to ensure ongoing sustainability), and five cohorts of parents (n=335) attended training workshops. This represented a significant number in the 3 countries, which have a combined population of just over seven million and low rates of diagnosis. Positive impact of workshops and materials was identified by pre-and post-training surveys and follow-up interviews [3.4, 3.5, 3.6].

ESIPP revealed for the first time the significant impact of autism upon families living in south east Europe, with respondents in all three countries identifying their experience of stigma and isolation, as well as highlighting the training needs of practitioners and the inadequacy of local support [3.4, 3.5]: this led to the development of a further Erasmus+ project – ASD-EAST – to develop and train primary teachers.

3. References to the research

[3.1] Bramble, P., & Preece, D. (2020). Identifying impact in a transnational project providing parent education for families living with autism in south-east Europe. *Journal for ReAttach Therapy and Developmental Diversities*, 3(1), 4-13. <https://doi.org/10.26407/2020jrtd.1.26>

[3.2] Preece, D., & Trajkovski, V. (2017). Parent education in autism spectrum disorder – a review of the literature. *Croatian Review of Rehabilitation Research*, 53(1), 128-138. <https://doi.org/10.31299/hrri.53.1.10>

[3.3] Preece, D., Symeou, L., Stošić, J., Troshanska, J., Mavrou, K., Theodorou, E., & Frey Škrinjar, J. (2016). Accessing parental perspectives to inform the development of parent training in autism in south-eastern Europe. *European Journal of Special Needs Education*, 32(2), 252-269. [2]. <https://doi.org/10.1080/08856257.2016.1223399>

[3.4] Troshanska, J., Trajkovski, V., Jurtoski, F., & Preece, D. (2019). The impact of ASD on Macedonian families and their experience of parent education. *Journal of Special Education and Rehabilitation*, 19(3-4), 127-138. <https://doi.org/10.19057/jser.2019.44>

[3.5] Stošić, J., Frey Škrinjar, J., & Preece, D. (2020). Families of children on the autism spectrum: experience of daily life and impact of parent education. *Support for Learning*, 35(2), 205-221. <https://doi.org/10.1111/1467-9604.12300>

[3.6] Preece, D., & Bramble, P. (2018). *Equity and Social Inclusion through Positive Parenting: Final Report*.

The outputs were funded by the European Commission under Erasmus+ grant 2015-1-UK01-KA204-013397. The value of the grant was EUR432,210.

4. Details of the impact

ESIPP resulted in a breadth of impacts for a number of specific audiences. Parents of children with autism were the principal target group, and it was towards them that the project's energies and activities were principally focused. However, it was acknowledged that, in order to achieve this aim, the project would necessarily impact a number of other groups, such as the teachers and professionals working with children with autism and their families. Impacts were also sought and identified with regard to the institutions and organisations participating in the ESIPP project. Finally, the project sought to bring about longer-term and sustainable impact by embedding parent education in autism within Croatia, Cyprus and the Republic of North Macedonia and highlighting the need for further development within the field of autism in these countries.

Increasing the knowledge, skills and confidence of parents of children with autism

Impact case study (REF3)

Before ESIPP, only a handful of parent trainings – limited in scope and often expensive – were provided in Croatia, Cyprus and North Macedonia [3.3]. Through the ESIPP project, 335 parents from across Croatia, Cyprus and North Macedonia were provided with free parent education from 2015-2018. Since September 2018, a further 154 parents have been trained, with 489 parents trained in total [5.1, 5.2]. This is a significant proportion of families living with autism in these countries. For example, North Macedonia's Macedonian Scientific Society for Autism's register lists 210 individuals with autism; we trained 143 families, which represents 68% of the population [5.1, 5.2]. In Croatia, 1036 individuals were identified under 18: 182 families were trained there, almost 18% of families [3.3]. No statistics are available regarding the number of children with autism in Cyprus. Post-training surveys and interviews identified that participation in ESIPP workshops improved parents' knowledge, skills and confidence regarding their children with autism, increased parental and child happiness, and provided social opportunities for many families [3.4, 3.5, 3.6, 5.1].

Parents testified to the project's impact:

- “In this country, we need to make very big changes for parents... The system should immediately send parents to obligatory training such as the ESIPP training, to see everything we saw when we were on it.” (Mother – Skopje) [3.4, p. 135].
- ‘Those workshops are really good, for me, we have learned a lot and they explained a lot to us, how to behave in certain situations and everything’ (mother of a ten-year-old, Croatia) [3.5, p. 215].
- One North Macedonian mother stated that learning to interact differently with her child ‘almost cleared all the challenging behaviours’, leaving her child more relaxed and her family ‘feeling much calmer and confident’ [5.3].
- A Croatian family expressed similar results, stating that the ‘procedures and methods [they] learned about during the ESIPP training helped [them] to deal more easily’ with their child’s behavioural challenges, creating a ‘calmer, carefree and happier’ environment for their family [5.4].

The headteacher of Dr Zlatan Sremec school in North Macedonia testified that the ESIPP programme increased the ‘options of support for children with ASD in Macedonia’ and ‘made a significant impact on parenting style and parent mental health’ for those who participated in the training [5.5]. Overall, the parents and families who participated in the trainings demonstrated a ‘deeper understating of the autism spectrum condition and are more confident in using different strategies in order to support development of communication, social and emotional regulation skills’. Accordingly, they have continued to use the training ‘both at home and at school as a tool for preventing and managing challenging behaviour’ [5.5]. This was also confirmed by the school’s special teachers, who are ‘noticing significant and positive outcomes in general behaviour in students with ASD’ and stronger understanding and engagement from parents [5.5].

Increasing training for professionals working with children with autism

Since 2018, national/municipal governments and agencies in North Macedonia and Croatia have funded training, using ESIPP materials [5.2]. This has led to over 2,300 professionals being trained, including teachers in all North Macedonian special schools, and students attending the only programme training special educators in Croatia [5.2]. The training materials have also been incorporated into the MA programme at the University of Zagreb, the only such programme for special educators in Croatia. This has improved professional expertise and competence amongst teachers in the region, with teachers in Croatia stating that ESIPP training provided ‘good evidence-based practice’ and ‘helpful materials’ [5.6]. Additionally, the materials have been made available online in Croatian, which has provided parents and professionals with an invaluable resource [5.6]. This is corroborated by Cypriot

Impact case study (REF3)

teachers who testify to the practical strategies they learned and applied in the classroom [5.7], while teachers in North Macedonia also report improved confidence and skills [5.8].

- 'I gained ...many practical strategies and finally understood how to properly handle children with ASD who may be included in my classroom. I also mentioned some of these to my colleagues, who were impressed and also started using them' (teacher, Cyprus).
- 'We need this kind of training, with exact information about everyday practice' (teacher, North Macedonia)

Transforming organisational approaches to inclusive education

As a result of the skills and knowledge developed through participation in the project, schools and NGOs involved in ESIPP are at the forefront of practice with regard to inclusive pedagogy, parent education and autism in their countries. As well as increased personal and professional competencies, participation led to instrumental strategic change in working practices. For example, the Centar za Autizam in Zagreb, changed their approach from one 'primarily based on working with experts' to one where they 'began to systematically educate parents of children with ASD in our Centre' [5.9]. As such, the project 'not only affected and have impact to us who worked directly, but also changed [the] entire institution, and indirectly the parents of children with ASD' [5.9].

Furthermore, the project enhanced partners organisations' national profile within Croatia. Due to the ESIPP project, the Ministry of Science and Education has partnered with the Centar za Autizam and the University of Zagreb's Faculty of Education and Rehabilitation [another ESIPP partner] to develop a 'new curriculum for the education of children with ASD at the national level' [5.9].

Increasing support and funding from policy makers for autism training

Presentations to policy-makers gathered at ESIPP conferences in Croatia, Cyprus and North Macedonia led to continued funding of parent education by national and municipal governments and other agencies; as well as use of ESIPP materials and funding of ESIPP partners to deliver training to professionals in Croatia, Cyprus and North Macedonia. As a result, over 2700 further parents, professionals and students in the region have received training since the project's end [5.2]. The quality of ESIPP's work led to policymaker support for the development of teacher training via the subsequent ASD-EAST project [5.10].

Before ESIPP, training materials in local languages that contained accurate information and evidence-based practice in autism, were extremely limited or inaccessible in these countries. Limited access to training, lack of funding (particularly within the former Yugoslav nations) and linguistic barriers made parents and professionals alike vulnerable to unsupported, unreliable and sometimes dangerous practice regarding autism. This project revolutionised parental and professional understanding. The continued funding and use of ESIPP materials will ensure that accurate information remains available to parents and professionals in the years to come.

5. Sources to corroborate the impact

[5.1] ESIPP Impact Report

[5.2] ESIPP post-project impact table.

[5.3] Testimonial from parent, North Macedonia, undated.

[5.4] Testimonial from parent, Croatia, 2 July 2020.

Impact case study (REF3)

[5.5] Testimonial from head teacher, North Macedonia, 6 July 2020.

[5.6] Testimonial from professionals, Croatia, 13 July 2020.

[5.7] Teacher Testimonial Cyprus, undated.

[5.8] Testimonial from trainer, North Macedonia 14 July 2020.

[5.9] Testimonial from Centar za Autizam, Croatia, undated.

[5.10] Letter from Croatian Education and Teaching Agency, 6 March 2018