



Developing parent education in autism in south east Europe: Introduction to the ESIPP project

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What is ESIPP?

- 3 year project running from September 2015-August 2018
- Funded by the European Commission (Erasmus+ Programme, Strategic Partnership)
- 9 funded partner organisations universities, charities and educators from five European Countries
- Focus parent education and training for parents of children on the autism spectrum in 3 south-east European countries where diagnosis and service provision in autism is limited and developing

ESIPP – Objectives of the partnership

- Develop an evidence-based model for delivering parent education in autism
- Develop a core curriculum and locally appropriate training materials
- Use these materials to provide parent education to Croatian, Cypriot and Macedonian families living with autism
- Evaluate the effectiveness of the materials and the impact of the training using quantitative and qualitative data collection and analysis
- Share the materials with stakeholders and make recommendations to policyand decision-makers across Europe

Why does parent education in autism matter?

- Positive effects of parent education:
 - Helps parents to understand their children with autism
 - Helps reduce stress in the family
 - Improves skills supports the child's learning, as well as family functioning
 - Improves social, educational and economic outcomes for those with autism and their families
 - Can reduce need for long term dependence on external support (that may or may not be there)

Parent education – Benefits and problems

- Range of parent education models in existence
- Some based on specific approaches (e.g. TEACCH, ABA)
- Some more eclectic: e.g. NAS EarlyBird, Spectrum/Reflections (Northants)
- But...
 - Can be issues about attendance, child care, waiting times, access, distance, intrusiveness
 - Generally based on US/UK models: these may be unavailable in or inappropriate for other settings



Developing the curriculum and training materials

Parent education curriculum and materials

- Approx. 12 hour education programme— Positive Approaches to Autism
- 6 core modules
 - Introduction to autism
 - Using structure and visual supports
 - Sensory sensitivities
 - Communication
 - Social development and interaction
 - Understanding and managing challenging behaviour
- Also extra modules on specific issues (e.g. eating, sleeping, puberty)



Parent education events



- Five sets of training events for Croatian, Cypriot and Macedonian parents 2016-2018 (c.300 in total)
- Trainings across the counties
 - e.g. Skopje, Veles, Ohrid, Bitola
- Local training teams being developed to support sustainability

Parent education events



- Parent education events have comprised
 - Core training curriculum
 - Extra modules on specific issues
 - Lectures
 - Group activities
 - Opportunities for individual consultation



Evaluation

- Gathering data from multiple sources to rigorously evaluate the project
 - Pre-training, post-training and follow-up questionnaires to all parents and carers attending training
 - Includes Quality of Life evaluation instrument (*CarerQoL*, Hoefman 2014)
 - Interviews with sample of parents
 - Trainer keeping reflective diaries throughout project
 - Trainer focus groups
 - Document analysis training materials (different versions)



Evaluation (continued)

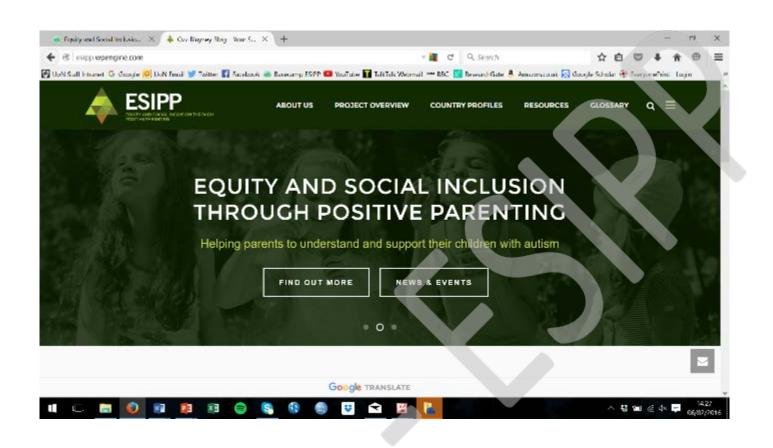
- Project Advisory Group
 - Parents, individuals with autism, professionals from Germany, Luxembourg, Netherlands and United Kingdom
- External Project Auditor
- Progress, interim and final reports to and audit by European Commission and UK Erasmus+ national agency
 - Full funding dependent on successful acceptance of final report

Key findings so far (Cohorts 1 & 2)

- Total parents trained in cohorts 1 and 2 = 108 (CR = 43, CY = 29, MK = 36)
- Positive impact
 - Improvement of everyday life, behaviour, communication
 - Increased understanding of autism and awareness of factors that may negatively affect child and family life
 - Improved ability to manage situations
 - Significant impact on parental happiness and ability to handle family stress
 - Opportunity to meet and interact with other parents

What have we done so far Sharing information about ESIPP 2015-1-UK01-KA204-013397

Sharing information about ESIPP – website and social media



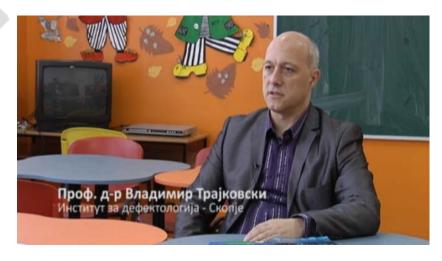
- Website <u>www.esipp.eu</u>
- Quarterly e-newsletter
 - PLEASE SUBSCRIBE AND FOLLOW OUR PROJECT
- Twitter and Facebook
 - @ESIPP_EUROPE
 - ESIPP project



Sharing information about ESIPP – conferences and TV



- Conferences in the project countries...plus UK, Ireland, Serbia, Denmark and Brazil
- TV programmes in the project countries





Sharing information about ESIPP – academic journals







Open Access, available to all

Getting people's views about ESIPP

Parent and professional conferences in:

- Zagreb (March 2017)
- Northampton (June 2017),
- Skopje (November 2017)
- Cyprus (March 2018)











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