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

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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 policy- and 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
What have we done so far?
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
What have we done so far
Evaluating the project
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)

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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
Sharing information about ESIPP – website and social media

- Website [www.esipp.eu](http://www.esipp.eu)
- Quarterly e-newsletter
  - PLEASE SUBSCRIBE AND FOLLOW OUR PROJECT
- Twitter and Facebook
  - [@ESIPP_EUROPE](https://twitter.com/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

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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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