ESIPP

EQUITY AND SOCIAL INCLUSION THROUGH
POSITIVE PARENTING

PARENT EDUCATION PROGRAMME (PEP) CURRICULUM

Equity and Social Inclusion through Positive Parenting

INTRODUCTION

Autism is a lifelong condition which affects about 1% of the population (or approximately 7.5m European citizens) as well as those who live with them and care for them.

The presence of autism can be extremely challenging to parents and other family members, and autism has been identified as causing greater family and parental stress than any other disability. The condition can challenge traditional parenting styles and cause parents to feel deskilled and disempowered. The presence of autism within the family can negatively affect the educational achievement, employment opportunities and social inclusion of mothers, fathers, siblings and the individuals with autism themselves.

Teaching parents to understand the condition, and to work effectively with schools and other professionals, has been shown to be effective in improving outcomes for individuals with autism and their families. However, though such parent education programmes have been developed in e.g. Western Europe and the USA, there is little or no availability of such programmes or materials in many areas within Europe, for example in the Balkan/Eastern Mediterranean region.

In order to address this inequity, the ESIPP strategic partnership was developed, involving universities, non-governmental organisations and the parents of children with autism. The objectives of this partnership are:

- To develop an evidence-based model for delivering parent education in autism that can be used across Europe
- To develop a core curriculum and ecologically valid parent education training materials
- To use these materials to provide parent education to families living with autism in areas where it has previously been difficult or impossible to access: Croatia, Cyprus and the Former Yugoslav Republic of Macedonia
- To evaluate the effectiveness of the materials and the impact of the training using quantitative and qualitative data collection and analysis
- To share the model curriculum, tools and materials with stakeholders and make recommendations to policy- and decision-makers.

INITIAL IDENTIFICATION OF THE CURRICULUM

To identify the content of this model curriculum, a number of activities were undertaken. A literature review of parent education in autism was undertaken (Preece & Trajkovski 2017), as well as an internet search and audit of current parent education models. This activity identified 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

Parents in Croatia, Cyprus and the FYR of Macedonia were surveyed regarding their training interests and needs. Respondents exhibited high interest in parent education seminars and workshops, with almost 90% wishing to attend such events. There was some national variation between the responses of the parents, with statistically significant differences between countries in 13 topic areas across all 6 domains. This supports the concept that no single training model would be appropriate across the three countries, and that consideration must be given to local content and local delivery methods.

The partnership prioritised training in areas where > 60% of respondents indicated interest. Eight such areas were identified with regard to Cyprus, 12 for Croatia, and 21 for the FYR of Macedonia. Five topics were identified as areas of need for training by > 60% of respondents across all the three countries. These were:

- Strategies for enhancing my child's communication (Domain II)

- Strategies on facilitating my child's interaction with other children (Domain V)

- Sensory integration and development (Domain III)

- General information on behavioural management strategies (Domain IV)

- Identifying and/or developing socialisation opportunities (Domain V)

Curriculum development activity focused upon these topic areas (whist of course paying heed to and seeking to address the other topics prioritised within individual countries). These five topics address communication, socialisation, sensory issues and behaviour. These are core difficulties in autism, and it is not surprising they were identified as important. These topics are considered key in parent training and interventions focusing on communication, playing with peers and positive, proactive approaches to problem behaviour have been identified as educational priorities for children with autism by the National Research Council (2001). Table 1 identifies how the key parental priorities have been integrated within the modules of the programme.

TABLE 1: PRIORITIES ADDRESSED WITHIN THE PARENT EDUCATION PROGRAMME

Domain	Description	Where addressed
Topics identified as areas of need for training by >60% of respondents in each country		
Domain II	Strategies for enhancing my child's communication	Module 4: Exploring Communication
Domain V	Strategies on facilitating my child's interaction with other children	Module 5: Social Development and Interaction
Domain III	Sensory integration and development	Module 3: Managing Sensory Sensitivities
Domain IV	General information on behavioural management strategies	Module 2: Practical Strategies to Manage Behaviour through Visual Structure Module 6: Understanding and Managing Challenging Behaviour
Domain V	Identifying and/or developing socialisation opportunities	Module 5: Social Development and Interaction
Additional priority areas: identified by >60% of respondents in Croatia and FYR of Macedonia		
Domain II	Awareness and help in the community	To be addressed by local trainers
Domain V	Issues on family's socialization and social life	Module 5: Social Development and Interaction
Additional priority areas: identified by >60% of respondents in Cyprus and FYR of Macedonia		
Domain V	Strategies on facilitating my child's interaction with other family members	Module 5: Social Development and Interaction
Additional priority areas: identified by >60% of respondents in FYR of Macedonia only		
Domain IV	Strategies on dealing with sexuality and relevant adolescence issues	Non-core training only
Domain II	Methods of high tech alternative communication (AAC): (e.g. digital devices)	Module 4: Exploring Communication (verbal discussion)
Domain II	Methods of no & low tech alternative communication (AAC): (cards, boards, signing)	Module 4: Exploring Communication
Domain IV	Strategies on changing specific behaviours at home and in the community	Module 2: Practical Strategies to Manage Behaviour through Visual Structure Module 6: Understanding and Managing Challenging Behaviour
Domain IV	Issues of sexuality and/or relationships	Non-core training only
Domain VI	Structuring the home environment for safe and interesting leisure activities	Module 5: Social Development and Interaction
Domain IV	Strategies on developing child's self-care skills	Module 2: Practical Strategies to Manage Behaviour through Visual Structure Non-core training
Domain IV	Structuring home environment to support skills development and behaviour	Module 2: Practical Strategies to Manage Behaviour through Visual Structure Module 6: Understanding and Managing Challenging Behaviour

THE ESIPP CURRICULUM AND PROGRAMME

Project partners have developed a training programme, presented within a series of six modules, that seeks to:

- support parents to develop an understanding of the nature, presentation and experience of autism
- nurture parents to develop a range of strategies that can be implemented to help address some of the many needs these children and their families face.

The content of each module presents the latest best practice as recognised by autism practitioners and experts in the field, as well as including the perspectives and individual accounts of individuals on the autism spectrum themselves.

It is hoped that participation in the modules will develop parental confidence, assisting them in making and implementing self -help strategies that will go some way toward easing the great demands that caring for children with autism requires.

Each module is designed to increase parents' knowledge, building upon the information learned in previous modules and extending it further. The content of the modules promotes the use of positive strategies and is based around the following topics: an introduction to autism spectrum conditions, behaviour, the use of visual structure, sensory issues, communication challenges and the building of social skills. In addition, three non-core modules were added to meet requests for information on puberty issues, and on sleeping and eating issues.

THE SIX MODULES - OBJECTIVES

Module 1: AN INTRODUCTION TO AUTISM SPECTRUM DISORDERS

The objectives for this module are:

- To establish a common understanding and knowledge about Autism Spectrum Disorders
- To help parents understand the unique profile of differences, strengths and difficulties for their child.

Activities highlight what knowledge parents may already have about the condition, and provide chances for parents to reflect upon their child's presentation of autism in greater detail.

Module 2: PRACTICAL STRATEGIES TO MANAGE BEHAVIOUR THROUGH VISUAL STRUCTURE

The objectives for this module are:

- To help parents utilise their child's visual learning strength to increase understanding and reduce stress.
- To develop an awareness of the different types of visual structure that can be helpful for individuals with autism:
  - Physical structure (the environment)
  - Schedules (what to do and when)
  - Work systems (how to do it, breaking down an individual task into visual steps)
  - Visual prompts (objects, photos, pictures and words)

Parents have the opportunity to look at a variety of visual prompts and schedules, and are encouraged to make similar, suitable support materials that will be useful for their child.

Module 3: MANAGING SENSORY SENSITIVITIES

The objectives for this module are:

- To identify and discuss the 7 senses and how hyper and hypo sensitivity can present.
- To understand how sensory differences can impact behaviours.
- To learn strategies and develop "toolkits" for coping with the impact of sensory sensitivities.

Parents take part in activities that increase their knowledge about the senses and how their children may be affected due to their autism. Parents are encouraged to develop a sensory profile of their child, and to be able to use methods to help address those particular sensory needs.

Module 4: EXPLORING COMMUNICATION

The objectives for this module are:

- To explore the development and purpose of communication.
- To understand how Autism Spectrum Conditions can on impact expressive and receptive communication.
- To learn strategies for supporting communication and communication development.

Parents will have the opportunity to practise different communication methods for non-verbal children such as picture exchanges and simplified sign language.

Module 5: POSITIVE APPROACHES TO SOCIAL DEVELOPMENT AND INTERACTION

The objectives for this module are:

- To develop an understanding of the social differences associated with the autism spectrum.
- To understand how the development of play skills underpins successful social interaction.
- To explore practical strategies that aid the development of play and social skills.

Parents learn how to use everyday materials (such as mirrors), toys and games that can be used to foster and encourage social interaction in their children. Parents are taught to try and enter their child's world of interests, instead of trying to quash those behaviours. This develops opportunities for genuine interaction with their child.

Module 6: UNDERSTANDING AND MANAGING CHALLENGING BEHAVIOUR

The objectives for this module are:

- To consider how a person's autism and characteristic differences can impact on their behaviours
- To explore the underlying reasons why behavioural challenges may occur
- To identify practical strategies to prevent, manage and de-escalate challenging behaviours.

This session brings together the knowledge and understanding developed in previous sessions to identify these strategies (e.g. visual prompts).

NON-CORE MODULES

I t has also been identified that a suite of non-core additional modules may be helpful for families at different stages or with different needs. These were identified through the initial survey, through discussion with families during the training sessions, and in discussion with the ESIPP Advisory Group (comprising practitioner, parent and self-advocate representatives). Potential additional modules identified are:

- Exploring food/mealtime issues

- Exploring sleep issues

- Exploring issues relating to puberty and adolescence

- Preparing for adulthood

- Sharing the diagnosis with the individual

- Helping families address their emotional needs

While it has not been possible within the ESIPP project to develop materials for all of these topics, materials were developed to address the first three, and these have been trialled in all participating countries.

The aim of this session is to develop awareness of all the sensory, social, flexibility and communication issues that can

EXPLORING FOOD AND MEALTIME ISSUES

impact on eating a balanced diet and successful mealtimes. Practical strategies are then explored to help address the identified issues.

The aim of this session is to explore the impact of anxiety, physical differences, exercise and diet on poor sleep patterns. Strategies to help such as modifying the bedroom environment, bedtime routines, tackling causes of anxiety and developing

EXPORING SLEEP ISSUES

relaxation are all explored in more detail.

The aim of this session is to enable parents to address needs directly related to the onset of puberty in their children who

EXPLORING PUBERTY AND ADOLESCENCE ISSUES

have autism. This includes very challenging topics such as hygiene issues and sexuality.

NB These are not part of the core ESIPP curriculum and are not presented within the training materials on the Erasmus+ or ESIPP platforms.

DELIVERY METHOD

The aim is to create a relaxed and informal atmosphere where parents feel comfortable and can socialise with other parents and meet new people during the breaks.

There are a variety of practical activities and video clips used in each session of the programme to enhance interaction between parents and trainers. Real-life anecdotes to naturally illustrate points being made are used throughout. Parents are encouraged to write down questions as they think of them during the day and are answered by trainers at the end of each day.

For further information see the Trainer Notes which accompany the ESIPP Parent Education Programme training materials.

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