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ESIPP

EQUITY AND SOCIAL INCLUSION THROUGH
POSITIVE PARENTING

IMPROVING QUALITY OF LIFE OF PEOPLE ON THE AUTISM SPECTRUM AND THEIR FAMILIES THROUGH PARENT EDUCATION

Recommendations for Policy-makers

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ESIPP Project



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THE NEED FOR SUPPORT ACROSS EUROPE

It is estimated that 1% of the population is on the autism spectrum (around 7.5 million people in Europe)¹. If you include their families, autism touches the lives of over 30 million Europeans.

Autism affects the way a person communicates, understands and relates to others. Autistic people often have difficulty using and understanding verbal and non-verbal language. This makes it difficult to understand others and interact with them which hinders their inclusion in society. Autistic people form a very diverse group with a variety of needs. People on the autism spectrum and their families face discrimination in many areas of life.

Autism is a complex lifelong developmental condition that challenges traditional parenting styles. It often has a profound impact on the whole family due to the level of stress it may cause, as well as the emotional and economic pressures of caring for children requiring a high level of support. Some parents can feel deskilled and disempowered, especially if little information or support is available to them. It can lead to strong feelings of helplessness, with families ultimately resorting to putting their children in institutions.

Getting the right support and therapies as early as possible makes a substantial difference to autistic people and their outcomes in life. However, in many countries, access to early evidence-based therapy is still lacking and parents have a very important role to play in supporting their children to gain a better social understanding and develop to the full of their potential.

A LEGAL OBLIGATION TO PROVIDE SUPPORT

Supporting families is therefore of paramount importance and an obligation, according to the Preamble of the UN Convention on the Rights of People with Disabilities - ratified by the European Union and its member states:

“Persons with disabilities and their family members should receive the necessary protection and assistance to enable families to contribute towards the full and equal enjoyment of the rights of persons with disabilities”.

Article 23 on “Right on Respect for home and the family” provides that:

“States Parties shall ensure that children with disabilities have equal rights with respect to family life. With a view to realizing these rights, and to prevent concealment, abandonment, neglect and segregation of children with disabilities, States Parties shall undertake to provide early and comprehensive information, services and support to children with disabilities and their families”.

PARENT EDUCATION CAN HELP CHILDREN ON THE AUTISM SPECTRUM AND THEIR FAMILIES TO THRIVE

Research shows that providing accurate information about autism to parents, and teaching them to adapt their parenting using good autism practice, is effective in improving personal, educational and social outcomes for autistic people and their families². However, such support is extremely limited or non-existent in some European countries.

To help fill the gap, the ESIPP project (Equity and Social Inclusion Through Positive Parenting) was established in 2015. This is a 3-year pan-European collaboration, co-funded by the European Union Erasmus+, Key Action 2: Strategic Partnerships. Its purpose is to develop parent education in autism tailored to the needs of families and autistic people in South East Europe.

¹ Elsabbagh et al 2012; Fombonne, 2011; ADDM 2012; Mattila et al 2011; Saemundsen et al 2013; Baird et al 2011.

² Bearss et al 2015, Farmer and Reupert 2013.

PROVEN POSITIVE IMPACT

The ESIPP evaluation results demonstrate the very positive impact of this initiative on the lives of children on the autism spectrum and their families.

According to the evaluation of the education programme³:

- ✓ **More than 90%** of the participants declared that attendance has improved their understanding of autism;
- ✓ **More than 80%** reported improved child communication;
- ✓ **And more than 75%** identified improvements in overall family life, their ability to predict their child's behaviour and their ability to respond to concerns and comments from the broader family;

Overall parents said that their **quality of life and level of happiness had increased and that their everyday life had improved**. They also reported that attendance provided opportunities to meet other parents, reduced social isolation and provided a forum to network and raise their concerns.

In addition, previous research has evidenced that parent education and training can also lead to **improved social, educational and economic outcomes for autistic people and their families** as well as identify the importance of involving autistic people in developing training⁴.

The topics prioritised by parents across all three countries are as follows:

- Strategies for enhancing their children's communication
- Strategies on facilitating their children's interaction with other children
- Sensory integration and development
- General information on behavioural management strategies
- Identifying and/or developing socialisation opportunities

TESTIMONIES FROM PARENTS WHO TOOK PART IN THE TRAINING

"I wish I had the opportunity to attend this education when my child was diagnosed"

"Educators were great! There were very good examples, examples from life, each of us can recognize ourselves in them"

"I realized that visual support is very important... we are using it now and it really helps him to understand..."

"I really liked when we had opportunity to ask about our children and about specific problem so they showed us how to communicate with them..."

"Spending time with other parents was really valuable for me, we can understand and help each other with our experiences"

"I would definitely recommend this education to other parents and family members"

"We learned more things in two days than we did in 5 years. We take our son to so many therapies and nobody has told us so many details and ideas than you did. Thank you so much for this training"

³ Preece et al, 2017.

⁴ Guldberg et al 2017.

KEY RECOMMENDATIONS

E SIPP strongly recommends EU Member States to ensure the development of effective parent trainings to foster a “positive approach to autism” and respond to the need for support of millions of families across Europe. In line with the project’s findings, this will contribute to the full implementation of the UNCRPD.

Parent training is an effective way to empower families and people on the autism spectrum as well as to improve their quality of life, outcomes and inclusion in society.

ESIPP findings highlight the fact that:

Parents training have a significant impact on the quality of life of autistic people and their families and should therefore be supported and further developed:

- Parent training should offer **practical solutions and strategies** to help families and autistic people cope with the **evolving challenges** they face across the lifespan.
- Parent trainings and curricula should be **developed and delivered locally** to meet the needs expressed by families (in the widest sense), including other carers, and autistic people in **specific cultural and social contexts**.
- They should adequately **reflect the diversity** of people on the autism spectrum (e.g.: with and without a learning disabilities) and of their support needs.
- **Autistic people themselves should be involved** in designing and delivering the training as their personal experiences can inform about the support needs of autistic children adhering to the principle “nothing about us, without us”.
- **Sustainability should be ensured** through adequate resourcing and capacity building of local trainers, again taking fully into account the specific needs and context of the country/region.

Autistic people and their families face many structural obstacles that significantly impact on access to rights and ultimately their quality of life:

- Parent trainings must be accompanied by the **development of multi-sectoral support services** in the community, both for autistic people and their families (e.g.: diagnostic, early evidence-based intervention, education taking into account their support needs, life-long support, etc.).
- Autistic people and their families should receive **support to cope with stress**.
- It is strongly recommended to further develop training of a **wide range of professionals in Europe across relevant sectors**, including for teachers and educators.
- **A united voice can foster positive change**. It is important that education programmes support parents’ capacity to federate themselves and to become advocates for their children in the community.
- It is also necessary to provide adequate support to children and young people to develop the **capacity to advocate for themselves**, including through supported decision-making.