



## FAMILIES OF CHILDREN ON THE AUTISM SPECTRUM

# Families of children on the autism spectrum: experience of daily life and impact of parent education

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**Information and support for families of children on the autism spectrum is limited in south-east Europe. A three-year project, *Equity and Social Inclusion Through Positive Parenting (ESIPP)*, was established to develop and provide parent education (PE) in autism for families in Croatia, Cyprus and North Macedonia. This paper presents findings from Croatia regarding family life and the impact of PE. Data were collected via pre- and post-PE questionnaires and semi-structured interviews. Participants discussed the impact of autism on family life, the difficulty of obtaining a diagnosis, the importance of family support (and varying experience of formal support), common experiences of stigma and social exclusion and concerns for the future. The value and benefit of PE is identified, and recognition of its impact within Croatia has ensured its ongoing provision.**

**Key words:** autism, Croatia, families, family life, parent education.

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## Introduction: Parent education in autism and the ESIPP project

The presence of autism in the family may impact profoundly upon family life and wellbeing (Karst and Vaughan Van Hecke, 2012; Giallo *et al.*, 2013). Providing effective information and knowledge regarding autism to parents and family members has been identified as a priority by, among others, the Autism Education Trust in the UK (Jones *et al.*, 2008) and the World Health Organisation (2014). Such parent education (PE) can increase parental understanding; improve quality of life, efficacy and coping; and reduce anxiety and stress (Farmer and Reupert, 2013; Preece and Trajkovski, 2017).

However, PE in autism is not accessible by all and is limited or unavailable in many regions, including south-east Europe (Daniels *et al.*, 2017; Hansen *et al.*, 2017). A three-year European Commission-funded project, *Equity and Social Inclusion through Positive Parenting* (ESIPP), was established in 2015 to address this shortfall for families in Croatia, Cyprus and North Macedonia. The project partnership developed an innovative PE model, established training teams in the three countries, delivered PE to more than 300 participants and worked with policy-makers to ensure sustainability beyond the project lifespan. Findings regarding North Macedonian participants are published elsewhere (Troshanska *et al.*, 2018). This article presents findings from Croatian parents and caregivers, exploring their experience of family life with a child on the autism spectrum and the impact of PE.

### **Autism in Croatia**

Croatia, with a population of just over four million, became an independent country in 1991 and joined the European Union in 2013. Understanding regarding autism in the country is emergent, with no clear diagnostic policy or pathway (Ombudsman for Children with Disabilities, 2014). The Croatian Institute for Public Health estimates there are 3,000 individuals with autism in Croatia (Total Croatia News, 2019) – most of whom are under 18 years (Benjak, 2015) – suggesting an identified prevalence far below the worldwide median of 62 per 10,000 (Elsabbagh *et al.*, 2012).

Croatian parents of children diagnosed with autism report significantly lower subjective quality of life and general health perception than those of

typically-developing children (Benjak, 2011), and are at heightened risk regarding mental and physical wellbeing (Benjak *et al.*, 2009). Whilst some specialist services and parent organisations exist in Croatia (Preece *et al.*, 2017) (among them, partners in the ESIPP), PE regarding autism had previously been provided only on an *ad hoc*, unsustainable basis (Bohaček *et al.*, 2017), whilst generic disability education for parents lacked appropriate information and strategies (Starc, 2014). Reliable information in Croatia is limited: parents report being confused about the condition and appropriate interventions, and some have fallen prey to pseudoscientific, sometimes dangerous, approaches (Martinović and Stričević, 2016).

## Methodological approach

An initial survey of families with children on the autism spectrum identified training priorities across Croatia, Cyprus and North Macedonia (Preece *et al.*, 2017). Informed by these findings, a 12-hour PE programme and training materials were developed, addressing topics identified as important across all three countries: visual approaches, sensory issues, communication, social development/interaction and understanding/managing challenging behaviour. Two-day workshops incorporated interactive presentations and group discussions, plus opportunities for individual consultation and problem-solving. Seven Croatian professionals were trained to deliver PE; workshops were advertised via schools and parent organisations. Five self-selected groups of parents/caregivers ( $n = 114$ ) attended workshops between 2016 and 2018 in Osijek ( $n = 24$ ), Rijeka ( $n = 7$ ), Split ( $n = 34$ ) and Zagreb (two groups,  $n = 49$ ). These were provided on weekends, in accordance with parental preference (Preece *et al.*, 2017), and at no cost to participants, making PE accessible to those who could not afford private services. Evaluation combined quantitative and qualitative methods.

Pre- and post-PE structured questionnaires were developed to gather data from participants before and after attending workshops. The CarerQoL (Brouwer *et al.*, 2006) – a quality of life scale successfully used in previous research regarding experience of families living with autism (Hoefman *et al.*, 2014) – was incorporated within the questionnaires. Questionnaires also gathered data regarding participants' understanding of autism, confidence in supporting their child, expectations of PE and the impact of attendance. Quantitative data were analysed using IBM SPSS software.

A semi-structured interview schedule was developed to undertake interviews with parents/caregivers approximately three months after attendance. Interviews

explored participants' experience and understanding of living with a child on the autism spectrum, their experience of PE and its impact (if any). Data were transcribed and input into QSR NVivo software (Bazeley and Jackson, 2013), then analysed using qualitative thematic analysis (Guest *et al.*, 2012).

## **Sample**

### *Questionnaires*

Pre-PE questionnaires were completed by 93 of 114 participants who attended workshops (82%); 67 post-PE questionnaires were completed, a response rate of 59% (see Table 1). Such attrition is common in PE generally (Snow *et al.*, 2002) and with regard to post-education surveys (Harte and Stewart, 2010); Croatian ESIPP trainers identified parents wishing or needing to get back to their children as the main cause of non-completion.

### *Interviews*

Semi-structured interviews were undertaken with 13 parents of children on the autism spectrum aged 3–17 years. Interviewees were self-selecting, drawn from all five groups. Two interviewees were male and 12 were female; parental age ranged from 28 to 52 years (mean = 37 years). Further demographic data is provided in Table 2.

## **Some key findings and commentary**

### ***Daily life with a child on the autism spectrum***

#### *Impact of autism*

The CarerQoL collected data before PE regarding respondents' perceptions about caregiving and their experience of living with a child on the autism spectrum (see Table 3). Interview participants were also asked about these topics.

Nearly all respondents (n = 88, 94%) reported experiencing fulfilment caring for their child on the autism spectrum. However, not all aspects of family life with autism were positive. Almost 90% (n = 83) reported relational problems with their child and 84% (n = 78) found it difficult to combine caring for the child with other

**Table 1.** Details of respondents: pre- and post-parent education workshops

<i>Workshop</i>	<i>Location</i>	<i>Total number of participants (n)</i>	<i>Pre-workshop questionnaires (n)</i>	<i>Post-workshop questionnaires (n)</i>
1. April/November 2016	Zagreb	25	22	12
2. February 2017	Zagreb	24	22	20
3. July 2017	Rijeka	7	7	4
4. October 2017	Osijek	24	16	15
5. March 2017	Split	34	26	16
Total		114	93	67

**Table 2.** Demographic data concerning interviewees (n = 13)

<i>Group</i>	<i>City</i>	<i>Relationship to child</i>	<i>Age</i>	<i>Education level</i>	<i>Employment status</i>	<i>Age of child on autism spectrum</i>
1	Zagreb	Mother	32	Secondary	Employed	4
1	Zagreb	Mother	35	University	Employed	10
1	Zagreb	Mother	49	Secondary	Employed	17
2	Zagreb	Mother	28	University	Not in paid employment	3
2	Zagreb	Father	39	University	Employed	13
2	Zagreb	Mother	36	PhD	Employed	5
3	Rijeka	Mother	35	University	Employed	10
4	Osijek	Father	38	University	Employed	4
4	Osijek	Mother	34	Secondary	Employed	9
4	Osijek	Mother	39	Secondary	Employed	3
4	Osijek	Mother	40	University	Employed	4
5	Split	Mother	32	Secondary	Not in paid employment	3
5	Split	Mother	52	University	Employed	16

**Table 3.** Respondents' perceptions regarding their caregiving situations (n = 93)

	<i>no</i>		<i>some</i>		<i>a lot of</i>			<i>Did not answer</i>	
	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>	<i>n</i>	<i>%</i>		<i>n</i>	<i>%</i>
	I have	3	3	21	23	66		71	fulfilment carrying out my care tasks.
I have	9	10	56	60	27	29	relational problems with my child	1	1
I have	18	19	52	56	23	25	difficulties regarding my own mental health.	0	0
I have	15	16	47	51	31	33	problems combining my care tasks with my other daily activities.	0	0
I have	25	27	46	49	21	23	financial problems because of my care tasks.	1	1
I have	14	15	44	47	34	37	support with carrying out my care tasks, when I need it.	0	0
I have	29	31	45	48	19	20	problems with my own physical health.	0	0

daily activities. Nonetheless, as identified elsewhere (Preece, 2014a; Schaaf *et al.*, 2011), parents generally accepted the demands autism placed upon them, with family life revolving around the child.

*'Everything we do is tweaked to him. Leisure time is with him. Every opportunity we get, we go outside to the playground or just play at home, building blocks. My wife and I don't have time for ourselves'* (father of a four-year-old).

Many parents interviewed saw themselves as therapists, constructing family life to maximise the child's learning.

*'I am a mother but a therapist as well, during 24 hours'* (mother of a five-year-old).

In addition to undertaking interventions themselves, parents spent a considerable amount of time (and money) taking their children to a range of different private

therapies: for example, occupational therapy, sensory integration therapy, speech therapy and neurofeedback therapy.

*'Some days we have several therapies, which means we spend a lot of time in the car . . . She sleeps at home and when she wakes up, we come here for neurofeedback three times a week'* (mother of three-year-old).

Hastings and Johnson (2001) identify the stress families can experience in undertaking a therapeutic role. Croatian parents interviewed spoke of the mixed feelings that they experienced, wanting simply to be a parent to their child with autism, whilst at the same time feeling pressured to focus on maximising development.

*'We have to make time to be parents as well. We need to be parents as well. But I have a feeling, If I am more a parent to him, if I don't educate him, I am losing time. And that means always forcing something'* (father of a four-year-old).

Mothers of children with autism are at heightened risk of parenting stress (Barker *et al.*, 2014), and in Croatia, Benjak *et al.* (2009) have identified the vulnerability of parents of children with autism regarding their mental and physical wellbeing. Over 80% percent of respondents (n = 75) reported mental health problems, while 68% (n = 64) had problems with their physical health. Interviewees spoke of the efforts they undertook to maintain a positive outlook.

*'I think if we started crying, that we would cry for four days non-stop'* (mother of a sixteen-year-old).

Families living with autism often experience financial hardship (Sharpe and Baker, 2007), and over 70% of respondents (n = 67) reported financial problems due to their care tasks. Families in Croatia may also be paying for private therapies, or for educational support in the classroom (Lisak *et al.*, 2017), whilst systemic issues were a further source of difficulty.

*'Last year, we applied for disability money. They refused us because at the time she wasn't diagnosed. Four months later, she was diagnosed. I went back to change her diagnosis number and to apply for disability allowance. The social worker convinced me that it was not possible. I had to wait for two years for disability allowance'* (mother of three-year-old).



### *Difficulty in obtaining a diagnosis*

Research suggests that the prevalence of autism in Croatia is grossly underestimated (Benjak, 2015), particularly with regard to abler individuals (Petković *et al.*, 2015), and that diagnostic pathways are unclear (Ombudsman for Children with Disabilities, 2014). This was confirmed in the experience of parents, who told of spending years seeking a diagnosis for their child and being passed from professional to professional in their quest.

*'They didn't want to write it for seven years, because something might change'* (mother of a seventeen-year-old).

*'It is very hard to get a diagnosis in the spectrum. When he was 18 months old, experts wouldn't help us. We were sure something was wrong. He was finally diagnosed when he was something about five'* (mother of a nine-year-old).

### *Informal and formal support*

The wider family's importance in providing practical and emotional support where there is a child with a disability or autism has been identified in Croatia and more widely (Twyo *et al.*, 2007; Leutar and Oršulić, 2015); 84% of respondents (n = 78) reported receiving such support. Interviewees spoke further of the positive relationships and social opportunities these afforded the child with autism.

*'He likes to walk with grandpa around the neighbourhood... and go on the tram, that is their thing....and when school is out, he likes to spend weekends at grandpa's'* (father of a thirteen-year-old).

*'He has cousins in Otoka. He adores to go there. There he has six cousins and adores to visit them'* (father of a four-year-old).

Parent groups and associations were positively regarded and identified as sources of information and support.

*'The best advice came from parents who have older children with autism'* (mother of a five-year-old).

Professional support for families of disabled children in Croatia is often viewed as inadequate (Lisak *et al.*, 2017) and interviewees were critical of health care, social care and educational services. Educational inclusion in Croatia is limited, with fewer than 1% of children with an autism diagnosis fully included in mainstream education (Sekušak-Galešev *et al.*, 2015), and teachers often feeling that they lack the skills to make inclusive education work (Bukvić, 2014). A parent whose child had attended a mainstream preschool spoke of the difficulties experienced when her child started there.

*'I wanted an assistant for him. He was included in the nursery along with 23 other children and two teachers. For the first two months he didn't have the assistant. It was hell'* (mother of a three-year-old).

By contrast, parents whose children were able to access specialist autism provision reported positive experiences and spoke of the support that this provided. Such specialist provision is, however, limited, and mostly confined to a few urban areas within one of Europe's most sparsely-populated countries (Croatian Bureau of Statistics, 2018).

*'We are satisfied with school. They are available for us, we get information, what we don't know they help us'* (mother of a ten-year-old).

### *Stigma and social exclusion*

Croatian respondents, like families elsewhere (Daniels *et al.*, 2017), spoke of their experience of discriminatory behaviour and stigmatisation. In many cases, this was enacted through social exclusion, leading one parent to state that other people needed to understand that

*'autism is not a contagious disease, that that is not a reason you should separate your children from our children . . . the biggest challenge is society and lack of understanding'* (mother of a ten-year-old).

Parents told of how their children were excluded from social events such as birthday parties – *'they would invite the whole class, except him...'* – and of bullying and abuse from other children.

*'This boy was abusing him, psychologically and physically. There were bruises. I saw a kid stab a pencil into his back'* (father of a thirteen-year-old).

## Concern about the future

In common with parents of children with autism elsewhere (Watson *et al.*, 2013), participants worried about what the future may bring. These concerns centred on what was seen as a systemic shortfall within Croatia in terms of appropriate support, both for children and adults.

*'I am always afraid of how it will be when we are gone' (father of a thirteen-year-old).*

*'The system in Croatia doesn't provide care for young children or adults that have autism either. We imagine our children will work as a chef or waiter; but they will work only if parents provide them with it. I always thought I could open a bakery shop with cakes and muffins and that my child would bake. But the problem is that I won't live forever' (mother of a five-year-old).*

## Parent education

### *Impact and benefits of attending PE*

The 67 parents who completed post-PE questionnaires responded positively regarding PE. After attendance, three quarters felt they had a good understanding of autism, that they could help their child communicate and express their needs and were able to respond to family comments or concerns (see Table 4). This positive response was reinforced within the interviews.

*'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).*

Regarding what they considered the principal benefits of PE, over 90% of respondents identified the practical strategies included in the workshops, while large numbers also highlighted increasing their understanding of autism and learning new ideas to keep their children happy (see Table 5). Interview participants emphasised the importance of helping parents develop practical skills, such as the

**Table 4.** Respondents agree with the following statements after attending ESIPP parent education (n = 67)

<i>Statement</i>	<i>No</i>	<i>%</i>
I feel that I have a good understanding of autism	51	76
I can help my child to express his/her needs/or to communicate effectively	51	76
I can respond to broader family's comments and concerns about my child	50	75
I can predict when my child's behaviour will become difficult	47	70
I can communicate effectively with my child	46	69
I can manage situations so that problems are often prevented	41	61
I can handle family/siblings stress	28	42

**Table 5.** Main benefits of attending ESIPP parent education (n = 67)

<i>Area of benefit</i>	<i>No</i>	<i>%</i>
Practical strategies to use with my child	61	91
Ideas to keep my child happy	54	81
Increased knowledge about ASD	50	75
Social opportunities for my child	37	55
Developing a support network through meeting other parents	31	46

use of daily schedules (Knight *et al.*, 2015), picture exchange communication systems (Bondy and Frost, 2011) and 'social stories' (Gray, 1994).

*'Maybe most useful part was with making that schedule. I think that really helped'* (mother of an eight-year-old). *'We started using picture exchange after the workshop'* (mother of a five-year-old).

*'I would point out these social stories. I make them in power point, then print it, I got a "know how" from them and I could immediately use it, which is great'* (mother of a five-year-old).

Over half felt attendance provided potential social opportunities for their child, while, in common with PE elsewhere (Farmer and Reupert, 2013), the opportunity for social networking with other parents was also positively received by many.

### *Perceived parental happiness*

In addition to the domains identified in Table 3, the CarerQoL required respondents to identify their overall level of happiness on a scale from 0 (*completely unhappy*) to 10 (*completely happy*). Sixty-seven respondents completed the CarerQoL before and after PE. Analysis using the Wilcoxon signed-ranks test identified a statistically significant increase, with mean parental happiness rising from 6.42 before attendance to 7.13 afterwards ( $p = .012$ ). An increase was also noted among Macedonian parents attending PE (Troshanska *et al.*, 2018), suggesting attendance impacted on perceived parental happiness.

### *Further development*

While generally positive regarding PE, interviewees made a number of suggestions regarding delivery. These included offering a range of delivery models and considering grouping participants according to their children's age or developmental levels. Some parents sought more targeted advice regarding their children's specific needs, while others felt this to be outside the remit of a group education programme (mean attendance at workshops was 23).

*'I understand that the goal is to reach as many parents as possible, to help everybody, not to exclude someone'* (mother of a five-year-old).

These suggestions informed the planning of further PE in Croatia, which has continued after the project's conclusion. Local parent workshops have been run weekly – each evening session covering a single topic – for groups of up to 10 parents. Content is adjusted to ensure relevance to the developmental level of participants' children, and role-play and practicing skills have been incorporated into workshops.

## **Limitations**

Participants identified limitations regarding the delivery model, and further limitations were inherent within the project. Attrition regarding the questionnaires

has been discussed already; moreover, low response rate from Cypriot workshop participants precluded comparison across the whole project. All participants were self-selecting; their motivation to participate may have led them to perceive the impact of PE positively. Self-selection also led to parents of older children being under-represented in the interview sample. As the development of capacity was a key project objective, different combinations of trainers delivered the workshops. While integrity was maximised by all trainers using the same materials (including trainer notes), differences in delivery are inevitable. Further variation will have arisen due to participants' varying needs, experience and interests.

## Conclusion

This study explored and identified the challenges faced by families living with children diagnosed with autism in Croatia. The low identified prevalence suggests many more individuals are going undiagnosed, or experiencing diagnostic substitution. PE has been identified as helpful and empowering by the participants in this study. Bearss *et al.* (2015), writing within a US context, argue that PE is less effective than individualised behaviour management training in addressing behavioural problems. However, we would argue that within a context such as Croatia – where understanding about autism, access to appropriate services or professional expertise and accurate and trustworthy information in the local language are limited – such autism-specific PE is vital. Furthermore, group interventions such as PE are cost-effective when compared to other models of service provision (Preece, 2014b). This is particularly important when statutory support systems are underdeveloped and where resources are scarce. Within such a context, even two days of parent education can have a positive impact. We assert that PE in autism is an important intervention which should be accessible to all parents and caregivers of children with autism, regardless of location.

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