Environmental Barriers and Facilitators to Participation of People with Autism Spectrum Disorders: stakeholders' perspective

"When people not used to speaking out are heard by people not used to listening then real change is made."
(John O'Brien)

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Abstract

Introduction: Social participation is a vital construct in inclusive philosophies and practices across communities. People with Autism Spectrum Disorders have been facing autism-related and environmental participation restrictions, placing them at risk of social exclusion and institutionalization. A multinational project has been developed in order to identify vital facilitating factors and establish PCP system for persons with ASD and tools for facilitators, as well as a 'master class' course for facilitators in several south-eastern European countries.

The **aim** of the study is to identify the most common barriers to participation faced by individuals with ASD and to highlight facilitating factors that can be utilised in development of an autism specific PCP approach.

Methodology: a mixed methodology employing concurrent qualitative-quantitative triangulation design was used. The participants consisted of four groups of stakeholders: young people with ASD, parents & family members of children/young people with ASD, teachers, and professionals. The data was collected via interviews and questionnaires with participants from the mentioned groups, using closed-ended and open-ended questions.

Results: thematic analysis of the information gathered from the interviews and questionnaires was detailed by topics. Each topic was viewed with regards to barriers and facilitators to social participation.

Conclusions: people with ASD have unique support needs that are qualitatively different from other special needs and communities are lacking specific understanding and approaches in meeting those needs. Insights from key stakeholders' view point represents indispensable considerations in Person-Centred support for overcoming barriers to social participation and promoting health, equity and well-being of persons with ASD.

Key words: Autism Spectrum Disorders (ASD), social participation, barriers, facilitators, person-centred support, quality of life.

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1. Introduction

With the shift to a social model of disability, goals aiming to achieve 'inclusive communities' have been at the core of deinstitutionalization and disability policy. Terms such as 'inclusion', 'integration', 'participation', or 'involvement' have been used interchangeably and they are subject to multiple conceptualizations. In social justice and human rights framework, inclusion is considered a philosophy based on values aiming to maximise the participation of all in society and education by minimising exclusionary and discriminatory practices (Booth, 2005).

The International Classification of Functioning (ICF) model defines the terms 'Activity' and 'Participation'. Participation is defined as involvement in a life situation, and participation restrictions are problems an individual encounters in a life situation. Activities are defined as the execution of tasks or actions by an individual, and activity limitations are difficulties in executing activities. Although, clear distinction between activities and participation is given, activity limitations often lead to participation restrictions and both are associated with disability (World Health Organization, 2001). The ICF also addresses environmental factors that impact activities and participation. Environmental factors include the physical, social and attitudinal environments in which a person lives and interacts including but not limited to support and relationships, attitudes, and services, systems and policies.

Inclusion of people with disabilities is one of the principles constituting the European Pillar of Social Rights, where the right of people with disabilities to services that enable them to participate in society is clearly stated (European Commission, 2018). Individualised support has become common parlance in services for people with disabilities. Person-centred planning (PCP) is a recent approach aimed at achieving individualised support and improving the quality of life of people with ID. This approach is considered an effective practice in supporting children and adults with Autism Spectrum Disorders (ASD), to increase social inclusion, independence, choice and autonomy. However, more needs to be done in person-centred approaches to support children and adults with ASD (Beadle-Brown, Roberts, & Mills, 2009) in terms of their participation in the process, as well as the quality of the support plans and implementation.

The core defining features of autism – the dyad of impairments – comprise significant differences in developmental areas of (1) social interaction and communication and (2) flexibility of thought and behaviour, and can pose lifelong obstacles to aspirations of community living and independent lifestyles. People with ASD have unique support needs that are qualitatively different from other special needs and require specific understanding and approaches in order to be met (Posada, Garcia Primo, Ferrari, & Martín-Arribas, 2007). These characteristic autism-specific difficulties can, if not adequately supported, hinder the optimal developmental and social outcomes for the individual and place them at risk for social exclusion. ASD affects a broad spectrum of functioning; the condition is lifelong and consequently an individual's special differences are likely to persist into adulthood. The impairments in ASD can manifest themselves in differing ways over time and the child with an ASD can develop and mature, just like any other, with former problem areas receding into the background, while new and different problems may replace old ones. Because of the challenging behavior they may exhibit, and due to existing prejudices about their

capacity to live independently, autistic people are at an increased risk of institutionalization. Lack of support and adequate childcare available for children on the autism spectrum, as well as lack of information and training for families on how to meet the specific and complex needs of children, also contribute to this risk of institutionalization.

Challenges in implementing PCP with individuals with ASD have been previously identified. Robertson, Emerson, Hatton, Elliott, Mcintosh, and Swift (2006) reported that persons with ASD are less likely to participate in PCP than those in other disability groups, and that the plans for those who do participate tend to be of lower quality. Difficulties with social interaction and communication can make it challenging for individuals with ASD to participate actively in group activities, including planning meetings. High levels of social anxiety are also common in individuals with ASD (Kerns et al., 2014). This may serve as an additional barrier to effective participation in planning meetings. A third challenge is that the autism spectrum encompasses individuals with widely differing levels of adaptive behaviour, i.e. the ability of an individual to function within everyday environments. Interventions effective for those who exhibit more adaptive behaviours may not be appropriate across the entire spectrum (Standifer, 2009). Other than a recent paper by Hagner, Kurtz, May, & Cloutier, there have been no reports of attempts to utilize or adapt the PCP process specifically for individuals with ASD (2014).

Without support, people with autism are often unable to make informed choices, communicate their desires, plan for the future and advocate for themselves. Person-centred thinking and planning for people with ASD need to take into account qualitatively different, autism-specific support needs which in order to overcome barriers to participation in decision making, transitions and life planning. A multinational project funded by the European Commission has been developed in order to establish PCP system for people with ASD, tools for facilitators, as well as a 'master class' course for facilitators in several south-eastern European countries: Bulgaria, Cyprus, Greece, Italy, Macedonia and Romania.

The current study expands upon previous research by utilizing a mixed-methods design to identify the most common environmental barriers to participation faced by individuals with ASD and to highlight factors which facilitate participation and support strategies to overcome these barriers and inform the development of a PCP approach with specific considerations for persons with ASD.

2. Methodology

2.1. Research design

A mixed methodology employing concurrent qualitative-quantitative triangulation design was used to address the planned aims. A convergence model of triangulation enabled one phase data collection, separate analysis and merging of the two types of equally weighting data at the interpretation level. The rationale for this approach is to converge the findings, to assemble results that are more powerful than if only one method were used (Creswell & Clark, 2017).

2.2. Participants

The participants consisted of four groups of stakeholders: young people with ASD, parents and family members of children or young people with ASD, teachers, and professionals (experienced practitioners from various disciplines special educators, social workers, psychologists, therapists, counsellors or persons/families with ASD). They provided data for a person with ASD diagnosed by an expert clinician. One hundred and twenty-seven participants were recruited from the community in six countries: Bulgaria, Cyprus, Greece, Italy, Macedonia and Romania. The sampling frame was purposive using several recruitment tools including, flyers, emails, posters, and word of mouth sent to public and private centres and organizations who support children with ASD and their families. Snowball sampling was also used in order to reach a broader base of relevant stakeholders. No incentives were provided for participating. The intention of recruitment was to have an even distribution of participants across the stakeholders; however, due to challenges with recruiting youth, the majority of participants were parents/guardians and service providers. Data were collected by self-reports from persons with ASD (n=11); and reports from parents/guardians (n=54), teachers /educators (n=18), volunteers (n=2) professionals (n=42) as informants on behalf of a person with ASD. Demographic data of the subjects is given in Table 1.

Table 1 Demographic overview of sample

Variable	Categories				
Sex	Male (n=81)	Female (n=28)	Prefer not to say (n=18)		
Age	0-4 (n=7)	5-18 (n=74)	18-24 (n=38)	25-39 (n=4)	40+ (n=4)
Education	Nursery school/kindergarten (n=2)	Elementary school (n=92)	High school (n=26)	Bachelor's degree (n=3)	Master's degree (n=3)
Countries	Bulgaria (n=5)	Cyprus (n=10)	Greece (n=28)	Italy (n=12)	Macedonia (n=67)	Romania (n=5)
Socio-economic status	Low (n=9)	Lower middle (n=99)	Upper middle (n=19)	High (n=0)	
Family status	Married (n=2)	Single (n=106)	Other (n=19)		
Work status	Employed (n=5)	Unemployed (n=12)	Family care (n=33)	Student (n=77)	
Area of living	Urban area (n=84)	Semi urban area (n=33)	Rural area (remote areas included) (n=10)		
Preferred means of communication (Multiple answers)	Oral communication (n=71)	Oral + Visual prompts (n=38)	Written instructions (n=18)	Pictures, images or photos (n=49)	In-tray and/or out-tray (n=6)	Body and sound (gesture, motor i.e. pulling) (n=11)

2.3. Research Procedure

Data were collected via interviews and questionnaires with participants from the mentioned four stakeholder groups, using closed-ended and open-ended questions. Informed consent was obtained from all individual participants included in the study. The research complies with The General Data Protection Regulation 2016/679 in EU law and The European Code of Conduct for Research Integrity (European Science Foundation & All European Academies, 2011). Although interviews were the preferred method of gathering data and accumulating ideas, due to scheduling challenges, the researchers offered to communicate in a written format with participants who could not attend interviews. We conducted 67 interviews, while 60 participants were given a hardcopy of the questionnaire or a webpage link to participate in an online questionnaire. The data collection took place simultaneously at all locations, from February to April 2019.

2.4. Questionnaire design

The questionnaire was designed to assist in the development of a cross-country response to the need for mapping environmental barriers and facilitators to participation and inform the development of life planning tools for people with autism, that contribute to facing their barriers, in a more effective way. The questions were organized in two sections. The first section was concerned with demographic background information, while the second empirically informed section was concerned with several topics pertaining to the special challenges and behaviours of persons with autism. To facilitate further understanding the daily situations and routines which challenge and stress persons with ASD in various aspects and life stages, we included the following topics: anxiety (stress, sense of fear); difficulties in social interaction; isolation/loneliness; sensory issues; poor emotional expression; conflicts and aggression; task avoidance/boredom; repetitiveness and perseverance; memory issues; difficulties with

time management; pica, and "other issues". Each topic was discussed in the frame of four questions or sub-topics: (1) Is there any intervention/support in place right now? (2) What is working? (3) What is not working? (4) What would be required to help? Informants were advised to discuss/ answer only those themes that were relevant the specific person with ASD. Topics that did not represent an issue for the person with ASD were not discussed. Due to space constrictions here we present and discuss the results for social communication and interaction, emotional skills and anxiety.

2.5. Data analysis

Descriptive statistics were undertaken and open-ended questions were analysed using thematic analysis. Questionnaires and transcripts of interviews were coded and thematically analysed by two researchers. Thematic analysis involved collation of information coded with the same code, and sorting different codes into categories. The researchers independently coded several transcripts by using short phrases or words that were derived from the informants' words. Then they came together to discuss the codes and group the codes into categories based on similarity in concepts. This consensus meeting was used as the method of reference. After making sure that researchers had similar understanding on the concepts, they were assigned to code the rest of the transcripts individually. Finally, the researchers conjointly merged categories together and developed overarching themes (Thorne, 2000).

3. Results

Thematic analysis of the information gathered from the interviews and questionnaires was detailed by topics. Each topic was viewed with regards to negative practices that essentially serve as barriers to social participation and social inclusion, as well as the positive and effective approaches and necessary accommodations as facilitators to overcoming these barriers and enhancing social participation of children, youth and adults with ASD. One or more themes were identified per topic that captured important ideas about the data in relation to the research question that represent a pattern in responses.

3.1. Anxiety

The data show that 86.73% of the informants (n=98) regarded anxiety as an important life-planning issue for the person with ASD. Of this number, 67.35% (n=66) had been receiving intervention/support and 30.61% (n=30) had not been receiving intervention/ support at the time of the study (see Table 2).

Regarding the barriers related to anxiety, the results yielded two themes: attitudinal barriers and communication barriers. Examples of each theme detailed by category are given in Table 3.

Table 2 Frequency of the problem and available support, detailed by topic

Topic/Support need	Experiencing problems	Receiving intervention/support	Not receiving intervention/ support	"Other"
Anxiety	86.73 % (n=106)	67.35 % (n=71)	30.61 % (n=32)	2.04 % (n=3)
Difficulties in Social Interaction and Communication	68.14 % (n=86)	67.53% (n=59)	29.87 % (n=25)	2.60 % (n=2)
Isolation/Loneliness	68.14 % (n=86)	45.45% (n=39)	53.25 % (n=46)	1.30 % (n=1)
Poor Emotional Expression	70.80 % (n=89)	53.75%	70.80 % (n=89)	53.75%

Table 3 Negative practices regarding Anxiety

Theme	Category	Frequency	Example
	Negative approach	36% (n=35)	"Yelling, shouting, punishment, doesn't work at all, that's for sure, nervousness produces more nervousness"
Attitudinal barriers	Ignoring the problem/person	26% (n=25)	"…not reacting to the behaviour "
	Insisting on the stressor activity or setting	30% (n=29)	" …The environment which is noisy and doesn't allow quiet and peaceful place, the lack of knowledge and misunderstanding by the school staff, the inability of the person to say what is bothering him" "…if he stays in the room with a large number of people, the anxiety and distress will increase"
Communication barriers	Lack of effective communication	9% (n=9)	"using only verbal communication, without adapting to the best way of communication for the person, in our case that is visual prompts"

Regarding positive approaches and considerations the information gathered yielded three themes: Prevention, Relaxation and calming strategies/techniques, Professional support/treatment. Themes detailed by categories and respective examples are shown in Table 4.

Table 4 Positive practices regarding Anxiety

Theme	Category	Frequency	Example
	Identification of triggers	6% (n=8)	"Most important is to read the child's signals and work out what makes her feel anxious or stressed"
Prevention	Preparation for stressful situations	8% (n=10)	"…Planning and deciding together how the person will communicate if things are getting too much and what will happen next. Prompt cards and smart phones can be used for this. If the person gets anxious when there's a change in routine, daily or weekly visual schedules can help prepare him. When you know a change is coming up, for example no classes on summer holydays – we can show this on his schedule. We look at the schedule regularly with the person so that he knows the weekly routine will be different."
	Predictable structured day	5% (n=6)	"I wait to finish my task; I ask him a question - "Is he done?" Looking for eye contact. I always pre-prepare my son for the day's activities that are ahead of him, telling him how many hours he starts and ends every activity."
	Redirecting attention to favourite activities or topics	26% (n=33)	"We redirect his/her attention to something that he likes. Like Lego's, puzzles or videogames."
Relaxation and calming strategies/techniques	Retreat to safe, calm, quiet environment	13% (n=16)	"We speak in a calm tone to calm down; We limit the stimuli of the environment; We move the girl and accompany it to a favourite place of peace"
	Physical and breathing exercise	9% (n=11)	"Being sensitive to not overwhelm her with talking or directions I simply take out some bubbles and begin to blow them for her. If you can get a child to blow the bubbles off the wand, this can help them take some deep breaths."
	Talking, humour	7% (n=9)	"I respond by using humour, talking through the situation and this helps"
	Close contact, hugs	5% (n=7)	"I stop and give cuddling and hugging. This helps to melt the stress away and I offer place to which they can turn to when they feel scared or nervous."
	Deep pressure	5% (n=7)	"For me, one of the challenging parts was being hypersensitive

	stimulation (DPS), massage		to noise, light and big groups of people. I became overstimulated very easily; I invested in a weighted blanket, a popular form of DPS therapy. I was amazed at how much it helped alleviate my insomnia. Sleeping under 6kg of blanket calmed my heart rate when I got in bed and I started falling asleep faster and staying asleep. When I feel overwhelmed during the day, I wrap myself up in it and find the heaviness of the blanket to be very soothing."
	Music therapy	7% (n=9)	"[For us] Music is a very powerful tool when it comes to stress management"
	Sensory stimulation	5% (n=6)	"For my son sensory stimulation is very helpful. He goes to a special dark room with different lights and equipment. This really calms him."
Professional support/treatment	De-sensitization Gradual exposure to triggers	7% (n=9)	"He is afraid of dogs, then he is worrying. For more than a year, we've been leading him to an agricultural yard where there are different animals, including small dogs. The boy has a high level of understanding and his specialists tell about dogs, show a relationship of attachment to the animal. The degree to which the autistic perceives the dog as part of a community of animals has already been reached, and the fear has already fallen. The youth no longer hides and runs away from the animals."
	Pharmacological treatment	2% (n=2)	"I was extremely wary at first, refusing more than once to start it, but my daughter's behaviours [severe social phobia, aggression at other and herself] I finally broke and agreed to try it. The only downside we found was a huge increase in her appetite, and her weight. She still has meltdowns, but much less frequently. We had tried other medications, but knew within days that they didn't suit her. With this one, we had no problems. "

3.2. Difficulties in social interaction and communication

Social Interaction and Communication problems are considered an important aspect of supporting the person with ASD by 68.14% of the informants (n=77). Of these informants, 67.53% (n=52) had been receiving intervention/support and 29.87% (n=23) had not been receiving intervention/support at the time of the study. The same proportion of informants (68.14%, n=77) identified Isolati-

on/Loneliness as an important consideration in supporting individuals with ASD, from which 45.45% (n=35) had been receiving intervention/support and 53.25% (n=41) were not supported (Table 2). Thematic analysis of the negative aspects again revealed two themes: communication barriers and attitudinal barriers. Examples of each theme detailed by category are given in Table 5.

Table 5 Negative practices regarding difficulties in social interaction and communication

Theme	Category	Frequency	Example
Communication barriers	Lack of alternative communication means	56% (n=55)	"Pushing the child to use words only, and not offering alternatives. Typing for example. My child communicates by typing, she has taught herself to read and spell"
Attitudinal barriers	Negative approach	17% (n=17)	"Raising the tone of our voice or insisting on a task he cannot relate to, and punishment for noncompliance"
	Very low or very high expectation	27% (n=26)	"[In my past school experiences] The tasks was not at my level, I felt incapable."

The thematic analysis of the positive aspects revealed two themes: establishing effective communication; and creating opportunities for socialization. Examples of each theme detailed by category are given in Table 6.

Table 6 Positive practices regarding difficulties in social interaction and communication

Theme	Category	Frequency	Example
Establishing effective communication	Present information in a format they can use /understand	25% (n=24)	"We use a lot of pictures, schedules, short sentences, slowly speaking" "I find that clear and concise language, avoiding symbolic speech and also using gestures and pictures helps with understanding"
	Understand an autistic person's expressive communication	20% (n=20)	"With my non-verbal student, I have to be very attentive and present at the moment, most of the time really small gestures are communication, all behaviour is communication" "…[it's required to] provide alternative or augmentative communication"
Creating opportunities for socialization	Initiate conversation	12% (n=12)	"Asking questions, talking about his favourite topics "
	Build rapport/build on activities that the person enjoys	29% (n=28)	"Interaction happens spontaneously when we give time to get to know each other and the person feels they can trust me" "Successful interaction means respecting the wishes of the person. He likes the computer and this is how we interact. I make teaching materials that capture his attention"
	Social skills groups/clubs	14% (n=15)	"Including the user, I group sessions, where interaction with peers is supported by professionals"

3.3. Poor emotional expression

A large proportion (70.80%, n=80) of the informants stated that emotional expression needs to be addressed in life-planning efforts for the person with ASD. Of these, (n=43) 53.75% of the persons with ASD had been receiving intervention/support and 45.00% (n=36) had not been supported in dealing with this issue (Table 2). Thematic analysis of the negative aspects revealed three themes: communication barriers, attitudinal barriers and systemic barriers (Table 7). Analysis of the positive aspects revealed a single pattern in the responses: development of emotional skills and empathy (Table 8).

Table 7 Negative practices regarding poor emotional expression

Theme	Category	Frequency	Example
Communication barriers	Lack of functional communication	58% (n=57)	I often get called in the school because teachers and staff don't understand what is the reason for his problem behaviour… and doesn't get help that he needs"
Attitudinal barriers	Negative approach	24% (n=23)	"…Putting pressure on him/her, shouting, negative reinforcement for behaving in inappropriate ways."
Systemic barriers	Lack of expert support and resources	18% (n=18)	"There is a need for support in the area of emotions that is not addressed enough. Material resources are lacking, also knowledge how to teach this skills"

4. Discussion

People and families living with ASD face many barriers stemming from autism-related impairments but also environmental factors, affectting not only the individual with ASD but also family functioning and quality of life (Preece & Trajkovski, 2017). We discuss barriers to participation and facilitators related to social interaction and communication, emotional skills

and anxiety, as perceived by relevant stakeholders. To the best of our knowledge, no other relevant or similar studies from Southern and Eastern European countries are currently available.

Table 8 Positive practices regarding poor emotional expression

Theme	Category	Frequency	Example
Development of emotional skills and empathy	Expanding the emotional vocabulary	22% (n=22)	'' labelling emotions in everyday situations helps my child learn new emotion words and their meaning''
	Identifying the emotions in self and others	32% (n=31)	''following an teaching intervention about emotions, and learning facial expressions, he is much better in recognising emotions in various social occasions''
	Appropriately responding to emotions in self and others	56% (n=55)	''… [The psychologist is] Supporting my daughter in dealing with intense emotional reactions…''

4.1. Social communication and interaction

Social interaction and communication difficulties and complementary isolation/loneliness are key aspects of supporting the person with ASD. Yet, a significant number of individuals in our sample (n=23) and (n=41) were not supported regarding social interaction/communication (29.87%) and isolation/loneliness (53.25%) challenges. Thematic analysis of the perceived barriers revealed two themes: communication barriers and attitudinal barriers. Attitudinal barriers related to social communication and interaction refer to a negative approach to dealing with problem situations as well as expecting too much or too little from the person with ASD. These barriers stem from inaccurate beliefs or perceptions about a person's ability based on assumptions and a lack of direct knowledge. This type of barrier impacts accessibility on all levels since most of the other barriers are rooted in attitudes as well.

People on the autism spectrum are just as likely as their typically-developing peers to enjoy engaging with others in activities that interest them, although other people often presume differently (Jordan & Caldwell-Harris, 2012). Difficulties in social communication are a core diagnostic criterion for autism and they present in a spectrum of ways. Some individuals on the autism spectrum may seek social opportunities and may initiate social interactions themselves; others may enjoy social situations and interactions when they are initiated effectively by others. Many have a genuine desire for friendship but may find the process of making and sustaining friendships difficult.

In a novel study by Ghanouni et al., involving key stakeholders, limited understanding of social situations has been identified as one of the main barriers to participation for children with ASD. The report shares a powerful quote "He did not understand and no one else seemed to understand him" (Ghanouni et al., 2019, p. 1) describing the social experience of a child with ASD. Namely, there are two particular social communication differences experienced by many people on the autism spectrum which provide insight into why social interactions are often challenging: predicting and interpreting others' behaviour, and receptive and expressive communication differences.

Persons with autism show delayed development of theory of mind (Baron-Cohen, Leslie, & Frith, 1985; Frith, 1994) which may impact their social interactions. Theory of mind refers to the understanding that other people have different thoughts, desires and needs to you. It involves being able to "put yourself in someone else's shoes" (Trajkovski, 2004). He/she may have difficulty predicting and interpreting the behaviours of others and may also have trouble understanding the effects of their own behaviour on the people around them. Individuals on the autism spectrum often have difficulty recognising and understanding social cues and therefore do not instinctively learn to adjust their behaviour to suit different social contexts (Frith, 1994).

Communication problems have always been considered a core feature of ASD. Yet there are substantial and wide-ranging differences in how people with ASD communicate. That reflects not only the inherent variability of the condition, but also

the complexity of communication itself — encompassing the words we use, the order in which we use them, eye contact, facial expressions, gestures and other nonverbal cues. They might be slower to develop language, have no language at all, or have significant difficulties in understanding or using spoken language. Some children with ASD develop good speech but can still have trouble knowing how to use language to communicate with other people. They might also communicate mostly to ask for something or protest about something, rather than for social reasons, like getting to know someone. They may use some of the following to communicate with you: Gestures, crying, taking your hand to the object they want, looking at the object they want, reaching, using pictures, challenging behaviour, echolalia (the repetition of other people's words).

According to stakeholders in our sample, over half of the individuals with ASD required supports to communicate effectively. This refers to augmentative and alternative communication including a wide range of accommodations from thumbs up – thumbs down system, writing or typing their thoughts, or using an assistive device. The lack of an efficient two-way communication and understanding is detrimental to social interaction and is perceived as a communication barrier by relevant stakeholders. Support for alternative means of communication is found to be one of the strategies to facilitating participation in transition planning for young people with autism (Hagner, et al., 2014). This is in line with our results on supporting social communication and interaction by establishing effective communication. Because communication is inherently a two-way process, one aspect of this support may be presenting information in a format that persons with ASD can use, supporting their receptive communication skills. The other, equally important aspect may be providing appropriate alternative communication means and/or understating a person's expressive communication. A very important consideration in supporting social communication and interaction is providing opportunities for socialization . Stakeholders identified initiating conversation, building rapport and establishing peer social skills groups / clubs as being some of the ways to facilitate participation for persons with ASD. Findings in our study align

with previous literature that external supports and services can facilitate social engagement for persons with ASD (Ghanouni, et al., 2019).

4.2. Emotional skills

Social communication and interaction deficits in ASD are intertwined with impairments in emotional understanding, defined as the knowledge to identify and understand others' emotions by facial or bodily cues, and within specific social context (Harris, De Rosnay, & Pons, 2016). Research confirms that individuals with ASD show general impairment in emotion recognition from facial and body cues as well as voice (Fridenson-Hayo et al., 2016; Lozier, Vanmeter, & Marsh, 2014; Uljarevic & Hamilton, 2013). It is suggested that these challenges arise from altered attention to faces, specific processing deficits and styles, and abnormal neural circuits that mediate face perception (Dawson, Webb, & McPartland, 2005; Schultz, 2005). Although much less represented in scientific literature, it seems that individuals with ASD may also express affect atypically, which can also have a disruptive effect on by-directional social communication. In addition, difficulties with emotion regulation can have serious behavioural manifestations in ASD. Tantrums, uncontrolled outbursts, aggression, and self-injury are often interpreted as defiant or deliberate. While this interpretation is likely to be accurate in some circumstances, it is more often the case that these inappropriate behavioural reactions stem from ineffective management of emotional states in response to stress or overstimulation (Mazefsky & White, 2014).

The need to address emotional skills in support efforts and plans for people with ASD was indicated by a significant majority (71%) of the informants in our sample. Markedly, almost half (45%) had not been adequately supported.

Communication barriers (lack of functional communication) are an underlining theme throughout this study. Additionally, attitudinal barriers (negative approach) have been brought up as well as systemic barriers (lack of expert support and resources). Stakeholders also alluded to support related to challenges with reading and understanding emotions in others. Specifically, these include expanding emotional vocabulary, identifying emotions in self and others as well as

appropriately responding to emotions in self and others.

The findings from the current research are consistent with previous studies which suggest that interventions/support that target emotion comprehension are not universally available in schools (Ghanouni, et al., 2019) and that teacher support requires implementation of such interventions (Vasilevska-Petrovska, 2015). Supporting teachers may also to some extent resolve the systemic and attitudinal barriers in the area of the social-emotional development of persons with ASD. Emotional interventions may give wider positive qualitative changes in the socio-communication skills and in the overall development of the child with ASD (Rice, Wall, Fogel, & Shic, 2015). Thus, emotional understanding as a crucial construct for social understanding should be an integral part of educational interventions and programs for students with ASD, an area where technology based interventions have shown great potential (Vasilevska Petrovska & Trajkovski, 2019).

4.3. Anxiety

Although anxiety is not considered a core feature of ASD, anxiety disorders and other mental health disorders are the regarded as most common comorbid conditions which may stem, at least partly, from autism-related impairments (Trajkovski, 2018). The clinical presentations of distress and anxiety associated with any single characteristic of ASD are variable (Kerns, et al., 2014). For example, whereas some individuals experience debilitating fears and worries related to any change in routine, others are more flexible; and while some show little interest in social interactions, others show distress, worry and loneliness when their social bids are unsuccessful.

Frequent fear of loud sounds in addition to unusual phobias, such as fear of beards, toilet bowls, and mechanical objects, are described in numerous studies of youth with ASD, including Kanner's seminal paper on the disorder, and may be related to atypical sensory experiences (Kanner, 1943; Leyfer et al., 2006). Similarly, excessive worry is described in individuals with ASD around changes in the environment, changes in schedule and other circumscribed rather than generalized topics, with fears seemingly clustered around perseverative, obsessive and restricted features of ASD. Highly

rigid behaviors, such as verbal rituals, compulsions (e.g. closing doors, keeping sleeves rolled down), and rule-governed preferences (e.g. eating only food of one color, or only eating certain foods in certain places) can also occur and may be accompanied by distress (Leyfer, et al., 2006). Recent finding also suggest that social anxiety characterized by fears of humiliation and rejection predicts aggression in children with ASD (Pugliese, White, White, & Ollendick, 2013). Although results are not entirely consistent, there is evidence to suggest that at least some of the ASD population is physiologically hyper-aroused, particularly those who present with anxiety symptoms (Mazefsky & White, 2014).

Based on stakeholders' perceptions only, we report high prevalence of anxiety (87%) experienced by people in our sample. This is greatly larger than the suggested between 11 and 42% of people with autism that struggle with one or more anxiety disorders (Vasa et al., 2016). We may presume that the reported percentage in our sample includes anxiety-related problems which may not fit the diagnostic criteria for anxiety disorder. We also have to consider the difficulty identifying anxiety in someone who has autism because of overlapping symptoms, as well as difficulty identifying and expressing emotions and other internal feelings (Sikora, Vora, Coury, & Rosenberg, 2012). However, regardless of whether an official diagnosis is present, the reference reported is a subjectively perceived challenge faced by people with ASD and families. Considering the increase of daily stress and social isolation and decrease of overall quality of life caused by anxiety and other mental health problems among people with autism (Vasa, et al., 2016), one third of our sample is facing significant lack of necessary support. This condition places people in a vicious circle, as untreated mental health conditions can profoundly worsen autism's behavioural challenges, and thus additionally compromise social participation.

Analysing stakeholders' views, we have identified environmental attitudinal and communicational barriers related to anxiety in persons with ASD which need to be addressed in an effort of person-centred thinking and planning. Awareness raising and recognizing anxiety, in addition to setting up individualised support and services, is particularly important for the wellbeing of these individuals.

Prevention strategies can include identification of triggers, preparation for stressful situations, and providing a predictable and structured day. Helpful relaxation and calming strategies/techniques include redirecting attention to favourite activities or topics, retreat to safe, calm, quiet environment, physical relaxation and breathing exercises, humour, close contact/hugs, and deep pressure stimulation (DPS) massage. Professional support/treatment can include music therapy, sensory integration therapy, de-sensitization (gradual exposure to triggers), and pharmacological treatment.

This study highlights significant information from the viewpoint of key stakeholders. However, it should be viewed as only a preliminary investigation, and further in-depth research is recommended to corroborate these findings. Another limitation that needs to be considered is the limited demographic description of the informants, particularly regarding those with ASD. Despite the large sample size, persons with ASD are underrepresented as informants, in comparison to parents and professionals. Such individuals should be represented to a greater extent in future studies.

The reported prevalence of anxiety should be taken with caution, regarding the lack of information on the condition, the presence of a medical diagnosis, and possible additional mental health problems and other medical comorbidities.

Consecutive efforts should be directed at tools and methodologies for understating and incorporating autism-specific adaptations to current Person-Centred Practices for people with ASD. Likewise, towards empowering families and professionals to act as facilitators for Person-Centred services in transitions and life planning, enabling greater social participation and involvement in decision making for the persons with ASD. An important focus for future research should be to examine the effect of incorporating varying degrees and styles of accommodations in Person-Centred Support planning and implementation on transition and life planning outcomes for persons with ASC across the lifespan. Further research is also needed to investigate how local and cultural differences can be addressed within PCP support programs.

5. Conclusion

We have shown that people with ASD have unique support needs that are qualitatively different from other special needs and communities are lacking specific understanding and approaches in meeting those needs. The individualization and personalisation of support services is a crucial factor to promote health, equity and well-being of persons with ASD. This approach is also considered as an effective practice in supporting children and adults with Autism Spectrum Disorders (ASD), to increase social inclusion, independence, choice and autonomy. Insights from key stakeholders' view point represents indispensable considerations in overcoming barriers to social participation and increase decision making through Person-Centred support for people with ASD.

References

Baron-Cohen, S., Leslie, A. M., & Frith, U. (1985). Does the autistic child have a "theory of mind"? *Cognition, 21*(1), 37–46.

Beadle-Brown, J., Roberts, R., & Mills, R. (2009). Person-centred approaches to supporting children and adults with autism spectrum disorders. *Tizard Learning Disability Review, 14*(3), 18–26.

Booth, T. (2005). *Keeping the Future Alive: Putting Inclusive Values into Action.* Paper presented at the Forum: for promoting 3-19 comprehensive education.

Creswell, J. W., & Clark, V. L. P. (2017). *Designing and conducting mixed methods research*: Sage publications.

Dawson, G., Webb, S. J., & McPartland, J. (2005). Understanding the nature of face processing impairment in autism: insights from behavioral and electrophysiological studies. *Dev Neuropsychol, 27*(3), 403-424. doi: 10.1207/s15326942dn2703_6

European Commission. (2018). *European Pillar of Social Rights*. Luxembourg: Office for Official Publications of the European Communities.

European Science Foundation, & All European Academies. (2011). *The European code of conduct for research integrity*: European Science Foundation.

Fridenson-Hayo, S., Berggren, S., Lassalle, A., Tal, S., Pigat, D., Bölte, S., Baron-Cohen, S., Golan, O. (2016). Basic and complex emotion recognition in children with autism: cross-cultural findings. [journal article]. *Molecular Autism, 7*(1), 52. doi: 10.1186/s13229-016-0113-9.

Frith, U. (1994). Autism and theory of mind in everyday life. *Social development, 3*(2), 108–124.

Ghanouni, P., Jarus, T., Zwicker, J. G., Lucyshyn, J., Chauhan, S., & Moir, C. (2019). Perceived Barriers and Existing Challenges in Participation of Children with Autism Spectrum Disorders:"He Did Not Understand and No One Else Seemed to Understand Him". *Journal of Autism and Developmental Disorders*, 49(8):3136-3145. doi: 10.1007/s10803-019-04036-7.

Hagner, D., Kurtz, A., May, J., & Cloutier, H. (2014). Person-centered planning for transition-aged youth with autism spectrum disorders. *Journal of Rehabilitation, 80*(1), 4–10.

Harris, P. L., De Rosnay, M., & Pons, F. (2016). Understanding Emotion. In M. Lewis, J. M. Haviland-Jones & L. F. Barrett (Eds.), *Handbook of Emotions* (4th ed., pp. 293–306). New York: Guilford Press.

Jordan, C. J., & Caldwell-Harris, C. L. (2012). Understanding Differences in Neurotypical and Autism Spectrum Special Interests Through Internet Forums. *Intellectual and developmental disabilities, 50*(5), 391–402. doi: 10.1352/1934-9556-50.5.391.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous child, 2*(3), 217–250.

Kerns, C. M., Kendall, P. C., Berry, L., Souders, M. C., Franklin, M. E., Schultz, R. T., Miller, J., Herrington, J. (2014). Traditional and atypical presentations of anxiety in youth with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 44*(11), 2851-2861. doi: 10.1007/s10803-014-2141-7.

Leyfer, O. T., Folstein, S. E., Bacalman, S., Davis, N. O., Dinh, E., Morgan, J., Tager-Flusberg, H., Lainhart, J. E. (2006). Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. *J Autism Dev Disord, 36*(7), 849-861. doi: 10.1007/s10803-006-0123-0.

Lozier, L. M., Vanmeter, J. W., & Marsh, A. A. (2014). Impairments in facial affect recognition associated with autism spectrum disorders: A meta-analysis. *Development and Psychopathology, 26*(4pt1), 933–945.

Mazefsky, C. A., & White, S. W. (2014). Emotion regulation: Concepts & practice in autism spectrum disorder. *Child and adolescent psychiatric clinics of North America, 23*(1). 15-24. doi: 10.1016/j.chc.2013.07.002. Epub 2013 Aug 30.

Posada, M., Garcia Primo, P., Ferrari, M., & Martín-Arribas, M. (2007). European Autism Information System (EAIS) Report

on the 'Autism Spectrum Disorders Prevalence Data and Accessibility to Services' Questionnaire (Q-EAIS). Madrid, Spain: Research Institute for Rare Diseases, Instituto de Salud Carlos III. *Madrid, Spain Research Institute for Rare Diseases, Instituto de Salud Carlos III Available: http://ec. europa. eu/health/archive/ph_information/dissemin ation/diseases/docs/autism1. pdf [accessed 16 July 2019].*

Preece, D., & Trajkovski, V. (2017). Parent education in autism spectrum disorder – a review of the literature. *Hrvatska revija za rehabilitacijska istraživanja*; 53(1): 118–128.

Pugliese, C. E., White, B. A., White, S. W., & Ollendick, T. H. (2013). Social anxiety predicts aggression in children with ASD: clinical comparisons with socially anxious and oppositional youth. *J Autism Dev Disord, 43*(5), 1205-1213. doi: 10.1007/s10803-012-1666-x

Rice, L., Wall, C., Fogel, A., & Shic, F. (2015). Computer-Assisted Face Processing Instruction Improves Emotion Recognition, Mentalizing, and Social Skills in Students with ASD. *Journal of Autism and Developmental Disorders; 45*(7): 2176-86. doi: 10.1007/s10803-015-2380-2.

Robertson, J., Emerson, E., Hatton, C., Elliott, J., McIntosh, B., Swift, P., Krinjen-Kemp, E., Towers, C., Romeo, R., Knapp, M., Sanderson, H., Routledge, M., Oakes, P., Joyce, T. (2006). Longitudinal analysis of the impact and cost of person-centered planning for people with intellectual disabilities in England. *American Journal on Mental Retardation, 111*(6), 400–416.

Schultz, R. T. (2005). Developmental deficits in social perception in autism: the role of the amygdala and fusiform face area. *Int J Dev Neurosci, 23*(2-3), 125–141.

Sikora, D. M., Vora, P., Coury, D. L., & Rosenberg, D. (2012). Attention-deficit/hyperactivity disorder symptoms, adaptive functioning, and quality of life in children with autism spectrum disorder. *Pediatrics, 130*(Supplement 2), S91-S97.

Standifer, S. (2009). *Adult Autism and Employment: A Guide for Vocational Rehabilitation and Professionals.* DPS & Curators of the University of Missouri: Disability Policy and Studies. School of Health Professions, University of Missouri.

Thorne, S. (2000). Data analysis in qualitative research. *Evidence-based nursing, 3*(3), 68-70.

Trajkovski, V. (2004). *Autism.* Faculty of Phylosophy, Institute of Special Education and Rehabilitation (Handbook on Macedonian).

Trajkovski, V. Health Condition in Persons with Autism Spectrum Disorders. Journal for ReAttach Therapy and Developmental Diversities. 2019 Feb 17; 1(2):112–124 doi: 10.26407/2018jrtdd.1.12.

Uljarevic, M., & Hamilton, A. (2013). Recognition of emotions in autism: a formal meta-analysis. *Journal of Autism and Developmental Disorders, 43*(7), 1517–1526. doi: 10.1007/s10803-012-1695-5.

Vasa, R. A., Mazurek, M. O., Mahajan, R., Bennett, A. E., Bernal, M. P., Nozzolillo, A. A., Arnold, L.E., Coury, D. L. (2016). Assessment and treatment of anxiety in youth with autism spectrum disorders. *Pediatrics, 137*(Supplement 2), S115-S123. doi: 10.1542/peds.2015-2851J.

Vasilevska-Petrovska, I. (2015). *Implementacija na socio-emocionalni intervencii vo edukativniot tretman na decata so autističen spektar na narušuvanja vo Makedonija.* Paper presented at the Unapređenje kvalitete života djece i mladih, Ohrid, Makedonija.

Vasilevska Petrovska, I, Trajkovski, V. (2019). Efects of a Computer-Based Intervention on Emotion Understanding in Children with Autism Spectrum Conditions. Journal of Autism and Developmental Disorders. Online 09 July 2019; doi: 10.1007/s10803-019-04135-5.

World Health Organization. (2001). *International classification of functioning, disability and health: ICF*: Geneva: World Health Organization.