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Stakeholders' views on barriers and facilitators of optimal support of individuals with Autism Spectrum Disorder in Macedonia

Abstract

The aim of presented study was to explore barriers and facilitators of optimal support for social and developmental outcomes for people with ASD. The survey was based on the semi-structured interviews with parents of people with ASD, as well as professionals supporting persons with ASD. Thematic analysis of the data was viewed with regard to positive and negative practices that essentially serve as barriers and facilitators of optimal support of individuals with ASD.

The results showed three levels of perceived barriers and facilitators of optimal support: (1) individual – related to the level of autistic impairment, (2) attitudinal – related to social interpretation of individual behaviour and needs, and (3) systemic – related to the education and welfare approach and practice at macro level. Insights from viewpoints of key stakeholders represent indispensable considerations in promotion of health, equity and well-being of individuals with ASD and to inform the development of an individualized support system based on the person-centred planning approach.

Keywords: Autism Spectrum Disorder, barriers, facilitators, social participation, person-centred planning (PCP), Macedonia.

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Poglądy interesariuszy na bariery i czynniki ułatwiające optymalne wsparcie dla osób z zaburzeniami ze spektrum autyzmu w Macedonii

Streszczenie

Celem prezentowanego badania jest charakterystyka dystraktorów i facyliatorów regulujących osiągnięcie optymalnych efektów rozwojowych u osób z ASD. W badaniu zastosowano częściowo ustrukturyzowane wywiady z rodzicami osób z ASD, a także specjalistami wspierającymi osoby z ASD. Analizę tematyczną danych przeprowadzono w odniesieniu do pozytywnych i negatywnych praktyk, które zasadniczo stanowią bariery i czynniki ułatwiające optymalne funkcjonowanie osób z ASD.

Wyniki pokazały, że bariery i facyliatory ułatwiające ujawniają się na trzech poziomach funkcjonowania: (1) indywidualnym – związanym z natężeniem zaburzeń autystycznych, (2) postaw społecznych – związanym ze społeczną interpretacją indywidualnych zachowań i potrzeb, oraz (3) systemowym – dotyczącym administracyjnych (legislacyjnych i praktycznych) rozwiązań w zakresie edukacji i opieki społecznej. Informacje uzyskane od kluczowych interesariuszy wspierających osoby z ASD mają istotne znaczenie dla budowania systemu wsparcia, którego celem jest profilaktyka zdrowia, równouprawnienia i jakości życia osób z ASD, w ramach którego indywidualnie dostosowane oddziaływania wynikają z planowania zorientowanego na osobę.

Słowa kluczowe: zaburzenia ze spektrum autyzmu, bariery, ułatwienia, zaangażowanie społeczne, planowanie zorientowane na osobę (PCP), Macedonia

Introduction

Autism Spectrum Disorder (ASD) is a heterogeneous group of neurodevelopmental disorders, affecting an estimated 1% of the world's population; however, the evidence in Macedonia is not so well measured (Trajkovski, Vasilevska, Ajdinski, & Mirko, 2005). The core defining features of autism – the dyad of impairments (APA, 2013) – includes significant differences in developmental areas of (1) social interaction and communication, and (2) flexibility of thought and behaviour, which can pose lifelong obstacles to aspirations of community living and an independent lifestyle, greatly impacting the quality of life. Individuals with ASD have unique service needs that are qualitatively (not always) different from those of other individuals with special needs. At the same time, the diversity across the spectrum of ASD requires highly individualised support in order to achieve optimal social and developmental outcomes. Without support, people with ASD often face social exclusion and violations of basic human rights. Globally, individualised support has been widely acclaimed and has become common parlance in services for people with disabilities. Locally, there is very limited data on the availability of adequate services as well as the support needs of individuals with ASD in Macedonia. However, more and more often there are proposals addressed to parents, thanks to which they can develop knowledge and skills to support their child's development (Troshanska, Trajkovski, Jurtoski, & Preece, 2018).

Developing autism-specific understanding and approaches to individualised support is especially relevant in the context of deinstitutionalisation and development

of community-based services in Macedonia, along with enhanced efforts for educational inclusion of students with all types of special educational needs, including ASD. Person-centred planning (PCP) is the approach aimed at identification of educational learning needs and goals for pupils with special needs, including those on the autism spectrum, in order to help them achieve individualised support and improve the quality of their lives. PCP may have a positive, although moderate impact on some individual aspects of psychosocial functioning of persons with ID. It has been found to be effective in increasing individual participation in community activities and choice-making as well as enhancing social support for individuals with disabilities, specifically intellectual impairment (Verdonschot et al., 2009).

Little research has been done so far on the effectiveness of PCP for people with ASD, as this approach is focused on the use of linguistic and communicative functions that are impaired in people with ASD. Therefore, they require a special and individual adaptation of PCP to their specific capabilities. However, challenges in implementing PCP for individuals with ASD have been previously reported (Barnard-Dadds & Conn, 2018). The results of research on the effectiveness of the PCP approach provide conflicting information. PCP is associated with improved functioning in social networks, better contacts with family and friends, as well as greater involvement in social and group activities. Positive effects can be achieved if small and short-range goals are formulated, focusing first on developing individual strengths and needs, and then on agreeing future goals, and during PCP meetings, visual guidance is used in order to focus attention and specify abstract concepts (Robertson et al., 2006). On the other hand, studies conducted by Robertson et al., 2006 reported that people with ASD are less likely to participate in PCP than those with other disabilities, and the use of PCP had no impact on social integration, employment, physical activity, or emotions or behavior of people participating in the activities.

Barriers may stem in part from ASD-specific impairments, but also from environmental factors that play a role as participation barriers. Difficulties with social interaction and communication can make it challenging for individuals with ASD to participate actively in-group activities, including PCP meetings. High levels of social anxiety are also common in individuals with ASD. 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. ability of an individual to function within everyday environments. People who are experiencing adaptation difficulties and emerging behaviors, need in an unfamiliar and potentially stressful environment of PCP meetings to find acceptance of individual rituals and repetitive behaviors, the performance of which often provides them with emotional comfort and allows them to focus on deliberate action (Hagner, Kurtz, May, & Cloutier, 2014).

Approaches effective with those who exhibit more adaptive behaviors may not be effective across the entire autism spectrum (Standifer, 2009). As mentioned, inherent autistic characteristics can pose a challenge to effective participation in planning, decision-making and expressing one's opinions. In addition, environmental factors pose additional challenges to social participation of people with ASD. These may

include the physical, social and attitudinal environments in which a person lives and interacts, including, but not limited to, available support and relationships, attitudes, and services, systems and policies (WHO, 2001).

However, study previously carried out in Macedonia and other countries led us to the conclusion that people with ASD have unique support needs that are qualitatively different from other special needs and communities lack 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 people with ASD. The person-centre planning approach is also considered as an effective practice in supporting children and adults with Autism Spectrum Disorders, 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 (Vasilevska Petrovska et al., 2019).

Method

However, due to the fact that sometimes people with ASD have low insight in their own needs and the fulfilment process the presented research was based on the view of professionals who might have realistic but outstanding perspective, and on parental perspective, which might be the most informative. The research presented in this article was aimed at identifying the characteristics of the barriers and positive practice opportunities related to facilitating people with ASD to participate in real life daily situations, which might cause stress in them in various aspects and life stages.

Participants

The participants consisted of two groups of stakeholders: parents of adults with ASD, and professionals/service providers in the field of disability (practitioners from various disciplines including school teachers, special educators, social workers, psychologists, therapists, counsellors). The sampling frame was goal-directed and relied on several recruitment tools including emails and leaflets sent to public and private centres and organisations that support people 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. Data were collected from 67 informants, who were either parents ($n=37$, 92% mothers) of a person with ASD, or professionals ($n=30$, 89% female), who supported a person with ASD. The average age of the participants was 37.8 years ($SD = 6.7$). The demographic characteristics of the participants is described in Table 1.

Table 1. Demographic overview of participants (parents and professionals)

Characteristic	Frequency (%)	
	Parents (n=37)	Professionals (n=30)
Highest level of education completed		
High school	4 (10.8)	0
Bachelor's degree	27 (72.9)	22 (27.0)
Post-Bachelor's degree	6 (16.3)	8 (73.0)
Socio-economic status		
Low	7 (18.9)	0
Lower middle	23 (62.2)	4 (13.3)
Upper middle	5 (13.5)	26 (86.7)
High	2 (5.4)	0
Area of living		
An urban area	32 (86.5)	22 (73.3)
Semi urban area	3 (8.1)	8 (26.7)
Rural area (remote areas included)	2 (5.4)	0
Marital status		
Married	26 (70.3)	0
Divorced	8 (21.6)	0
Separated, single, or widowed	3 (8.1)	0
Years of experience		
<1	0	3 (10.0)
1–5	0	14 (46.6)
6–10	0	9 (30.0)
>10	0	4 (13.4)

Methods and procedure

The semi-structure interview was designed to get response for mapping the support needs relative to environmental and inherent barriers and highlighting positive practices and facilitators of people with ASD. The questions were organised in two sections. The first section collected demographic background information using closed questions, while the second, empirically informed section was concerned with several topics pertaining to the special challenges and behaviours of people with ASD. The second section employed questions on further understanding of the daily situations and routines that challenge and stress people with ASD in various aspects and life stages, we emphasised the following topics: difficulties in social interaction and communication, emotional skills, and repetitiveness and perseverance. Each topic was discussed in the "what's working – what's not working" framework. Informants were advised to discuss only those themes that were relevant to the specific person with ASD.

Data transcripts of interviews were coded and thematically analysed by the first and second authors. Thematic analysis involved collation of information coded

with the same code, and sorting different codes into categories. The transcripts were independently coded by researchers by using short phrases or words that were derived from the informants' words. Then codes were collected into categories based on similarity of concepts during consensus meeting served to establish a reference: after making certain that researchers had a similar understanding of the concepts, they independently coded portions of remaining transcripts. Finally, the researchers merged categories together and developed overarching themes (Thorne, 2000).

The research complied 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). The data collection, recording and transcription were conducted by the second author during February, March and April 2019.

Results

Needs and received support

In the sample, social interaction and communication problems were considered by 91.04% of the participants (n=61) as a necessary support area for the person with ASD. Among them, 68.85% (n=42) were receiving intervention/support and 31.15% (n=19) were not receiving intervention/support at the time of the study. Regarding emotional skills, a large portion of the participants (80.60%, n=54) stated that this area needs to be addressed in support efforts for the person with ASD. Among them, 55.56% (n=30) of the people with ASD were receiving intervention/support in dealing with this issue, while 44.44% (n=24) were not. Difficulties with flexibility of thought and behaviour were considered by 80.60% of the participants (n=54) as an area of difficulties for the person with ASD. Among them, 51.85% (n=28) of the people with ASD were receiving intervention/support at the time of the study and 48.15% (n=26) were not (Table 2).

Table 2. Frequency of experienced difficulties and available support, detailed by topic

Topic/area of difficulties	Experiencing problems	Receiving support	Not receiving support
Social interaction and communication	91.04% (n=61)	68.85% (n=42)	31.15% (n=19)
Emotional skills	80.60% (n=54)	55.56% (n=30)	44.44% (n=24)
Repetitiveness/perseveration	80.60% (n=54)	51.85% (n=28)	48.15% (n=26)

Thematic analysis

Thematic analysis of the information gathered from the interviews was carried out by the topic, each of which was viewed with regards to negative practices that essentially serve as barriers to social participation and social inclusion, as well as with regards to positive and effective approaches and necessary accommodations that serve as facilitators to overcoming these barriers and enhancing social participation of adults with

ASD. One or more themes were identified per topic that showed informative patterns of responses, providing insight into the research question. The analysis of positive and negative experiences of stakeholders across the three mentioned topics/areas of difficulties revealed three themes: (1) individual barriers and facilitators (2) attitudinal-social barriers and facilitators, and (3) systemic barriers and facilitator.

Individual barriers and facilitators

The identified individual barriers fall into two categories: (1) Lack of alternative communication means and (2) Lack of functional communication. Several facilitating categories were formed (1) Present information in a format the person can use/ understand, (2) Initiate conversation, (3) Build rapport/build on activities that the person enjoys, (4) Social skills groups/clubs.

The thematic analysis revealed two categories of facilitators: (1) Establishing effective communication, and (2) creating opportunities for socialisation. Examples of each category detailed by topic are given in Table 3.

Table 3. Individual barriers and facilitators

	Category	Topic	Freq.	Example
Communication barriers	Lack of alternative comm. means	Interaction	29% (n=11)	"Pushing the person to use words only, and not offering alternatives. Typing, for example, or pictures. My child communicates by typing; she has taught herself to read and spell"
	Lack of functional comm.	Emotional skills	37% (n=7)	"I often get called in the school because teachers and staff don't understand what is the reason for his problem behaviour... and he doesn't get help that he needs"
Communication facilitators	Present information in a format the person can use / understand	Social interaction and communication	35% (n=30)	"We use a lot of pictures, schedules, short sentences, speaking slowly" "I find that clear and concise language, avoiding symbolic speech and also using gestures and pictures help with understanding"
	Initiate conversation	Social interaction and communication	31% (n=27)	"Asking questions, talking about his favourite topics ", "being a positive model on how to start conversation"
	Build rapport/build on activities that the person enjoys	Social interaction and communication	13% (n=11)	"Interaction happens spontaneously when we allow time to get to know each other, and the person feels he or she 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	Social interaction and communication	12% (n=10)	"Including the user, I do group sessions, where interaction with peers is supported by professionals"

Attitudinal barriers and facilitators

The thematic analysis of the negative aspects revealed two categories of attitudinal barriers: (1) Very low or very high expectation in the area of social interaction and communication and (2) Negative/uniformed approach, across all areas of difficulties. The following categories were formed based on positive, facilitating practices: (1) Understand an autistic person's expressive communication, (2) Building on the persons' interests and obsessions, and (3) Understanding the function of the behaviour. Examples of each category detailed by topic are given in Table 4.

Table 4. Attitudinal barriers and facilitators

	Category	Topic	Freq.	Example
Attitudinal barriers	Very low or very high expectation	Social interaction and communication	47% (n=18)	"Presuming the person understands more or less than he actually does; he gets frustrated or loses motivation to communicate".
	Negative/uniformed approach	Social interaction and communication	24% (n=9)	"Raising the tone of our voice or insisting on a task he cannot relate to, and punishment for noncompliance".
		Emotional skills	47% (n=9)	"...Criticism, shouting, and using punishment is not working and is a negative experience for the person. We should not presume that he is acting out on purpose."
		Restricted and Repetitive Behaviors	38% (n=12)	"...the biggest mistake is to assume that they [teachers] must try to stop the motion. Interrupting the behaviour with shouting/talk in a loud voice is not the effective way. Everyone should have the same positive approach and think about what he [the person] can do instead"
Attitudinal facilitators	Understand an autistic person's expressive comm	Social interaction and communication	9% (n=8)	"With my non-verbal student, I have to be very attentive and present in the moment; most of the time really small gestures are communication – all behaviour is communication"
	Building on interests and obsessions	Restricted and Repetitive Behaviors	14% (n=4)	"... [I] favour the stereotypes in order to introduce other activities"
	Understanding the function of the behaviour	Restricted and Repetitive Behaviors	58% (n=16)	"I believe repetitive behaviours should be allowed to an extent. It's a mechanism that helps them de-stress or put things into place."

Systemic barriers and facilitators

The identified systemic barriers fall in the only one category: (1) Lack of expert support and resources, and was present across all areas of difficulties including emotional skills, restricted and repetitive behaviors and social interaction and communication. The analysis revealed two of facilitators' categories: (1) Available targeted interventions and (2) Available behaviour management systems. Examples of each category are given in Table 5.

Table 5. Systemic barriers and facilitators

	Category	Topic	Freq.	Example
Systemic barriers	Lack of expert support and resources	Emotional skills	16% (n=3)	"There is a need for support in the area of emotions that is not addressed enough. Material resources are lacking, as well as knowledge in how to teach these skills"
		Restricted and Repetitive Behaviors	62% (n=20)	"My child doesn't get the support he needs. There is no behaviour specialist in our community. This is a big problem for many parents that I know"
		Social interaction and communication	18% (n=11)	"Teachers and staff are not trained to support communication" "Assistive devices are not available"
Systemic facilitators	Available targeted interventions	Emotional skills	53% (n=28)	"after a teaching intervention about emotions and learning facial expressions, he is much better at recognising emotions in various social contexts"
			21% (n=11)	"... [The psychologist is] supporting my daughter in dealing with intense emotional reactions..."
	Available behavior management systems	Restricted and Repetitive Behaviors	28% (n=8)	"When we began to consider sensory problems and managed to reduce sensory discomfort, the stimming declined drastically" "He likes to chew on things, so we give him a bag of gummi bears that provide similar sensory input"

Discussion

Communication barriers and facilitators

In a novel study involving key stakeholders (Ghanouni et al., 2019), limited understanding of social situations has been identified as one of the main barriers to participation for a person with ASD. The report includes a powerful quotation – "He did not understand and no one else seemed to understand him" (Ghanouni, et al., 2019, p. 1) – that describes the social experience of a person with ASD. Namely, there are

two particular social communication differences experienced by many people on the autism spectrum that provide insight into why social interactions are often challenging: predicting and interpreting others' behaviour, and receptive and expressive communication differences.

People with ASD show delayed development of theory of mind, which may impact a person's social interactions. Theory of mind (Howlin, Baron-Cohen, & Hadwin, 1999) refers to the understanding that other people have different thoughts, desires and needs than you have. It involves being able to "put yourself in someone else's shoes" (Trajkovski, 2004). Individuals with ASD 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.

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 the communication itself — encompassing the words we use, the order in which we use them, eye contact, facial expressions, gestures and other nonverbal cues. People with ASD might be slower to develop language, have no language at all, or have significant difficulties in understanding or using spoken language. Some people 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 someone: gestures, crying, bringing the other's hand to the object they want, looking at the object they want, reaching, using pictures, challenging behaviour, and echolalia (repetition of other people's words).

In our sample, over half of the subjects required support to communicate effectively. This refers to augmentative and alternative communication including a wide range of accommodations, from a "thumbs up – thumbs down" system, writing or typing their thoughts, or using an assistive device. The lack of efficient two-way communication and understanding is detrimental to social interaction and is perceived as a communication barrier by relevant stakeholders. The same perception was identified related to emotional skills in our sample. Lack of functional communication related to emotional skills can lead to frustration and behaviour problems. Support for alternative means of communication is one of the strategies for facilitating participation in transition planning for youth with ASD (Hagner, Kurtz, May, & Cloutier, 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 people 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 socialisation. Stakeholders indicated that initiating conversation, building rapport, and establishing peer social skills groups /clubs may be some of the ways to facilitate participation for individuals with ASD. Findings in our study align with the literature that external support and services can facilitate social engagement in people with ASD (Ghanouni, et al., 2019).

Attitudinal barriers and facilitators

Attitudinal barriers related to social communication and interaction refer to misconceptions, stereotypes and prejudices, leading to negative approaches to dealing with problem situations, as well as to too big or too small expectations from a 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. People with ASD 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. Difficulties with social communication are a core diagnostic criterion for ASD and they manifest in a number of ways. Some people with ASD may seek social opportunities and may initiate social interactions themselves; others may enjoy social situations and interactions when they are effectively initiated by others. Many have a genuine desire for friendship but may find the process of making and sustaining friendships difficult.

The second core characteristic of ASD is reflected in markedly restricted and repetitive patterns of behaviours and actions, coupled with a strong desire to maintain sameness in the environment. These behaviours are now grouped together under one umbrella term, restricted and repetitive behaviours (RRB), which describes a heterogeneous range of behaviours. A dichotomy of RRBs has been proposed, comprising "lower-order" and "higher-order" RRBs. Lower-order behaviours can range from motor stereotypes such as repetitive rocking, hand-flapping and kicking to repetitive sensory behaviours such as repeated mouthing or smelling of objects. Complex rituals such as lining up, collecting or carrying objects around also fall under the term restricted and repetitive behaviors. These are thought to be associated with atypical development of either the person with lower intelligence quotients or with other comorbidities; in contrast, higher-order behaviours comprise more cognitively complex behaviours such as intense, narrow interest in certain objects, activities or topics, known as circumscribed interests, insistence on sameness and routines (Turner, 1999). Perseveration may also refer to the obsessive and highly selective interests of individuals with ASD, indicating an inability to switch ideas or responses. Early observations of RRB have been interpreted as evidence of impaired imaginative ability (Happé & Frith, 2006). It has been argued that a difficulty with imagination is the central difficulty of ASD, such that autistic individuals find it difficult to symbolically store abstract concepts from their experience and therefore have difficulties using such concepts when reacting to daily life or thinking about the future (Wing, Gould, & Gillberg, 2011). This results in an inflexibility of thought as a counterpart to behavioural inflexibility.

Misconceptions regarding emotional skills and regulations was also identified as a common barrier faced by people with ASD. Emotional regulation problems in people with ASD are often considered to be mischief, which results in a negative approach that hinders the social and emotional development. Negative practices regarding restricted and repetitive behaviors have also been reported and stem from a limited understanding of these behaviours and the variety of purposes that they serve.

Systemic barriers and facilitators

Very often persons with ASD face systemic barriers when accessing services. In our sample, stakeholders reported lack of expert support and resources for social skills (31%), emotional skills (44%), and restricted and repetitive behaviors (48%). Stakeholders alluded to support related to challenges with reading and understanding emotions in others. Specifically, three concepts came up: expanding emotional vocabulary, identifying emotions in oneself and others and appropriately responding to emotions in oneself and others. Impairments in emotion comprehension, defined as the knowledge to identify and understand others' emotions based on facial or bodily cues and within a specific social context, are closely linked to the social communication deficits in ASD (Vasilevska Petrovska, & Trajkovski, 2019). Difficulties with emotion regulation 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 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 findings from the current research are consistent with literature that interventions/support that target emotion comprehension are not universally available in schools (Ghanouni, et al., 2019) and that teacher support is needed for implementation of such interventions (Vasilevska Petrovska, 2015). Supporting teachers may also to some extent resolve the systemic and attitudinal barriers in social-emotional development of people with ASD. In our results, supporting the development of emotional skills and empathy is identified as a facilitating factor to optimal support of persons with ASD. Similarly, emotional interventions are considered to produce wider positive qualitative changes in the socio-communication skills and in the overall development of the person with ASD (Rice, Wall, Fogel, & Shic, 2015). Thus, emotion comprehension as a crucial construct for social understanding should be an integral part of educational interventions and programmes for students with ASD, an area where technology-based interventions have shown great potential (Vasilevska Petrovska & Trajkovski, 2019).

Systemic barriers (lack of expert support and resources) are evident in the context of managing restricted and repetitive behaviors in ASD. The results are in line with prior evidence that interventions are more likely to target social and communication domains than restricted and repetitive behaviors despite the prominence of such behaviours as management challenges, barriers to adaptive learning and a burden for families (Leekam, Prior, & Uljarevic, 2011). Unavailability of expert support and services represents a systemic barrier that needs to be addressed, given that 80%

of our sample is affected by restricted and repetitive behaviors. Related to this are the attitudinal barriers stemming from the lack of specific knowledge and assumptions, which are expected to decline simultaneously with systemic barriers.

Stakeholders have all responded in line with the notion that repetitive behaviours serve a purpose, and they have highlighted the need to understand the function of the behaviour, manage the environment, provide alternatives to the behaviour, build on interests and obsessions, and create more structure and predictability in the environment. There is encouraging support for behavioural approaches to intervention involving careful identification of triggers and functions, i.e. skill-based behavioural interventions and comprehensive interventions that address numerous aspects simultaneously. Early intervention programmes based on applied behavioural analysis focus on positive reinforcement and learning of alternative adaptive behaviours, while other intervention programmes take a different approach by focusing on enhancing the affective experience for the person with the goal of reducing overarousal and anxiety (Leekam, Prior, & Uljarevic, 2011). Similar barriers, facilitators as well as support needs in the area of social communication and interaction and emotional skills were identified in a cross-country response investigation in Bulgaria, Cyprus, Greece, Italy, the Republic of North Macedonia, and Romania (Vasilevska Petrovska, et al., 2019).

This indicates that the conditions for individuals with ASD across Southern and Eastern Europe are comparable, implying that a collaborative approach in dealing with this issue is advisable. This study highlights salient insights from the viewpoint of key stakeholders. However, it should be viewed only as a preliminary investigation, and further in-depth research is recommended to corroborate these findings. The limited demographic description of the informants, particularly regarding those with ASD, needs to be considered a limitation of the study. Despite the large sample, individuals with ASD were less represented as informants than parents and professionals. Such individuals should be represented to a greater extent in future studies.

Future efforts should be directed at tools and methodologies for understanding and incorporating autism-specific adaptations into individualised support for people with ASD. Likewise, future research should be oriented 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 people with ASD. An important focus for future investigations should be examining the effect of varying degrees and styles of PCP accommodations on transitions and life planning outcomes for persons with ASD across the lifespan. Further research is also needed to investigate how local and cultural differences can be addressed within PCP support programmes.

Conclusions

This paper describes the unique support needs of people with ASD as those needs relate to social communication and interaction, emotional skills and flexibility of thought and behaviour, which qualitatively differ from other special needs. Our results also

suggest that communities in Macedonia lack specific understanding and approaches in meeting those needs. The individualisation and personalisation of support services is a crucial factor to promote health, equity and well-being of people with ASD. This approach is also considered as an effective practice in supporting children and adults with ASD, to increase social inclusion, independence, choice, and autonomy. Insights from key stakeholders' viewpoints are indispensable considerations in overcoming the communication, systemic, and attitudinal barriers to social participation through incorporating appropriate accommodations to individualised support for people with ASD. The foundations of PCP should be implemented early on by teaching functional communication to young children with ASD as well as basic skills for making choices. Adequate adaptations that take into consideration all aspects of the condition are required, in order to create an enabling environment and give a voice to individuals with ASD.

The presented study seems to provide useful conclusions that the PCP approach should take into consideration the barriers faced by an individual with ASD. This conclusions closely resemble the conclusions to the similar research carried out in the UK by Robertson et al, in 2006. The information was collected regarding barriers to PCP every 3 months from key informants with the use of self-completion questionnaires. Results Barriers to PCP were widespread particularly in relation to: availability of trained facilitators, availability of services, lack of time and reluctance of people other than paid support staff to engage in the PCP process. Conclusions Services need to be aware of potential barriers in PCP so that strategies can be developed to overcome them, the first of which should be the ongoing training and support of facilitators.

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