

**Eötvös Loránd University, Faculty of Education and Psychology,
Doctoral School of Education, Special Education Module**

Thesis

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**'I just want him to be happy...' Opportunities for autistic
children and adults from a parent's perspective**

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1. INTRODUCTION

The main aim of autism-specific supports and services is to improve the quality of life and psychological well-being of autistic people and their families (EMMI, 2020; Lord et al, 2020; Reed, 2016; Stefanik, 2018b). Unfortunately, it is not currently evident that all autistic people, from childhood to old age, have access to appropriate quality, evidence-based, autism-specific support on an ongoing basis (MASZK, 2020; Stefanik et al, 2020). Although the difficulties in accessing support are not specific to autism, it appears that parents of autistic children face more difficulties in choosing educational institutions than typically developing children or children with other special educational needs (Parsons, Lewis & Ellins, 2009; Starr & Foy, 2012), and that there are even fewer services available for autistic adults (Anderson & Butt, 2018; Anderson, Lupfer & Shattuck, 2018; Song et al, 2022). No research has yet been carried out in Hungary to explore the factors influencing parents' decisions to support their autistic children, while data from the international literature can only be partially and cautiously applied to the situation in Hungary due to the different educational structures and other specificities of the autism-related support system. In this dissertation, we will examine the factors that influence the decision situations related to the support of their children from the perspective of parents raising/supporting autistic children and adults.

The dissertation - and the thesis booklet - are structured in three content units. The first unit (2. chapter) aims to outline the broader context of our research topic. The immediate international research background of our empirical study is discussed in the second unit (3. chapter), in the form of a systematic literature review. We present our exploratory empirical study using a qualitative research methodology approach in the third unit (4. chapter). The study is related to a sub-theme of a three-phase research series of the 'Autism in Education' Research Group of the Hungarian Academy of Sciences (HAS) – ELTE University (research phase 3/2; research ethics approval number KEB/2018/003). The aim of our study is to explore (1) the children's/adults' journeys in the service system (2) explore the perceived support and barriers parents face in accessing services/supports, (3) parents' perceptions of the quality of support, (4) their perceptions of their children's future, and (5) their suggestions for improving the service system. These objectives were pursued through a thematic analysis of semi-structured interviews with parents of 10 autistic children of school age and 12 autistic adults.

2. BACKGROUND

The definition of autism has changed considerably since it was first described (Asperger, 1944, in Frith, 1991; Kanner, 1943), but approaches from different disciplines still vary (Lord et al, 2020; Fletcher-Watson & Happé, 2020). In special education support, we now think of autism as a specific pathway of human development, in the context of neurodiversity, leaving behind the medical approach (Lord et al, 2020; Fletcher-Watson et al, 2019). Autistic people have a distinctive but highly diverse behavioral picture due to their different neurological functioning and cognitive psychological characteristics from neurotypical people (APA, 2013; Wing, 1996). However, despite the heterogeneity of the behavioral picture, it is also coherent, as autistic development essentially affects two behavioral domains, socio-communicative interactions and flexible behavioral patterns (APA, 2013; Csepregi & Stefanik, 2012; WHO, 2022).

In the comprehensive support of autistic people, above and beyond professional and methodological principles, it is essential to ensure the human rights of autistic people and to establish partnerships with the actors of support (Lord et al, 2020; Stefanik, 2018b). To ensure the quality of the work, it is essential that the support is individualised, based on objectives and using evidence-based methods and tools (Reed, 2016; Rutter, 2007; Stefanik, 2018a). The overarching goal is to improve the quality of life and psychological well-being of autistic children/adults and their families (EMMI, 2020; Stefanik, 2018b).

However, both international and national research suggests that autistic people and their parents have a lower quality of life and psychological well-being compared to people with neurotypical or other neurodiverse conditions and their parents (Eapen & Guan, 2016; Eapen et al, 2023; Vasilopoulou & Nisbet, 2016; Volgyesi-Molnar et al, 2024; Sonido et al, 2019; Wang et al, 2022). A number of influencing factors have been identified behind this, with one of the main factors emerging as access to support for autistic people (Chiang & Wineman, 2014).

There are opportunities in the service system available in Hungary to support autistic children and adults, but the results of research exploring the parental perspective show a worrying picture. Although some of the legal options are provided, there is a lack of sufficient and appropriate quality autism-specific support in some schools (MASZK, 2020), the number of support options available in adulthood is low, and the majority of adults do not receive autism-specific support (Kiss, 2010; MASZK, 2020; Stefanik et al, 2020).

3. SYSTEMATIC LITERATURE REVIEW

The aim of our systematic literature review is to comprehensively explore the perspectives of parents of school-aged autistic children and autistic adults on (1) their children's access to support/services, (2) satisfaction with support/services, (3) their children's vision for the future, and (4) suggestions for the service system. A further aim is (5) to draw a conceptual framework within which the empirical part of the doctoral research can fit.

3.1. Method

The protocol for the systematic literature review was developed in accordance with the recommendations of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) (Page et al, 2021). The literature search was conducted in November 2022 in four databases (Educational Resources Information Center (ERIC), PubMed, Scopus és Web of Science) using the same search strategy. The search was restricted to empirical studies published in English-language peer-reviewed journals in the last 20 years (2002-2022). A total of 9,595 results were obtained.

3.1.1. Screening of studies

After searching the databases and removing duplicates, the studies were screened according to the inclusion and exclusion criteria at three levels: first, the titles, then the abstracts, and finally the full texts (*1. figure*).

3.1.2. Selection and exclusion criteria

The selected studies were (1) empirical studies focusing on (2) parents (at least 50%) (3) of autistic school-age children (6 years or older) and/or autistic adults (at least 50%) (4) accessing support/services, making decisions, choices, satisfaction with support, future plans, and suggestions for the service system. The terms support/service refer to both autism-specific and non-autism-specific support/service that an autistic child or autistic adult of school age has received or is receiving.

We excluded publications that (1) included less than 50% of school-age autistic children (6 years or older) and/or parents of autistic adults, and (2) systematic reviews of the literature.

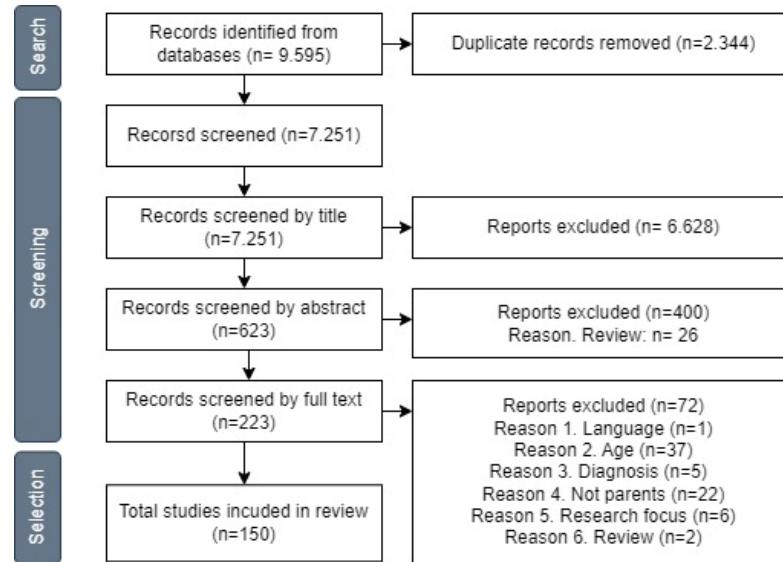


Figure 1. Steps in the selection and exclusion process.
(Figure based on PRISMA guidelines; Page et al, 2021)

3.1.3. Selection of studies

Following a three-stage screening process, 150 studies that met the above inclusion and exclusion criteria were included in the systematic literature review.

3.1.4. Characteristics of selected studies, research methodology approach

A more detailed review of the characteristics of the studies included in the systematic literature review and the methodological approach of the research reveals several aspects that also determine our results.

A look at the publication dates of studies shows that the number of studies is steadily increasing. While in the early 2000s only a few studies in these research foci were published, there has been a marked increase in the number of publications, especially from 2020 onwards (2. figure).

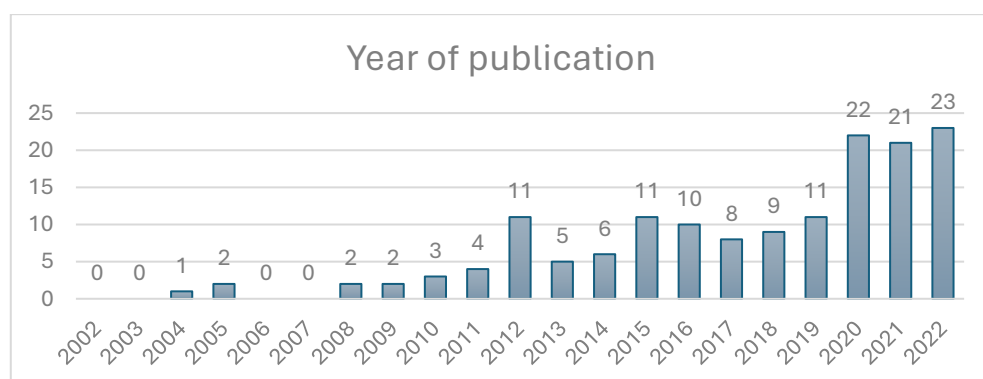


Figure 2. Distribution of studies included in the systematic literature review by year of publication

Based on the distribution of research foci of the included studies, we see that they mainly fit our first two research objectives – access to support (n=99) and perceptions of quality of support (n=79) – with fewer studies focusing specifically on parents' perceptions of their children's vision of the future (n=17) and parents' perspectives on improving services (n=26) (3. (1). figure).

The majority of the selected studies are qualitative (n=77), a minority are quantitative (n=52) and 21 studies use a mixed methods approach (3. (2). figure). 8 qualitative studies and 2 quantitative studies were published as part of a larger mixed methods study, and one quantitative study was part of a larger research sub-sample.

In terms of study participants, we see a strong shift towards school-age children (n=91), with far fewer studies specifically exploring the perspectives of parents of autistic adults (n=21). Some of the studies are mixed in their classification along age perspective (n=38) (3. (3). figure).

The studies included in the systematic literature review also differ in terms of which country(ies) or region(s) they focused on, which is a crucial issue due to the differences in the structure of the service system. The studies focus on different areas of the world, with data available for all continents except Antarctica, but the proportions are very uneven. The vast majority of studies are in North America and Europe; more than 80% are in an Anglo-Saxon (e.g. USA, Australia) or partly Anglo-Saxon country (e.g. Canada) (4. figure).

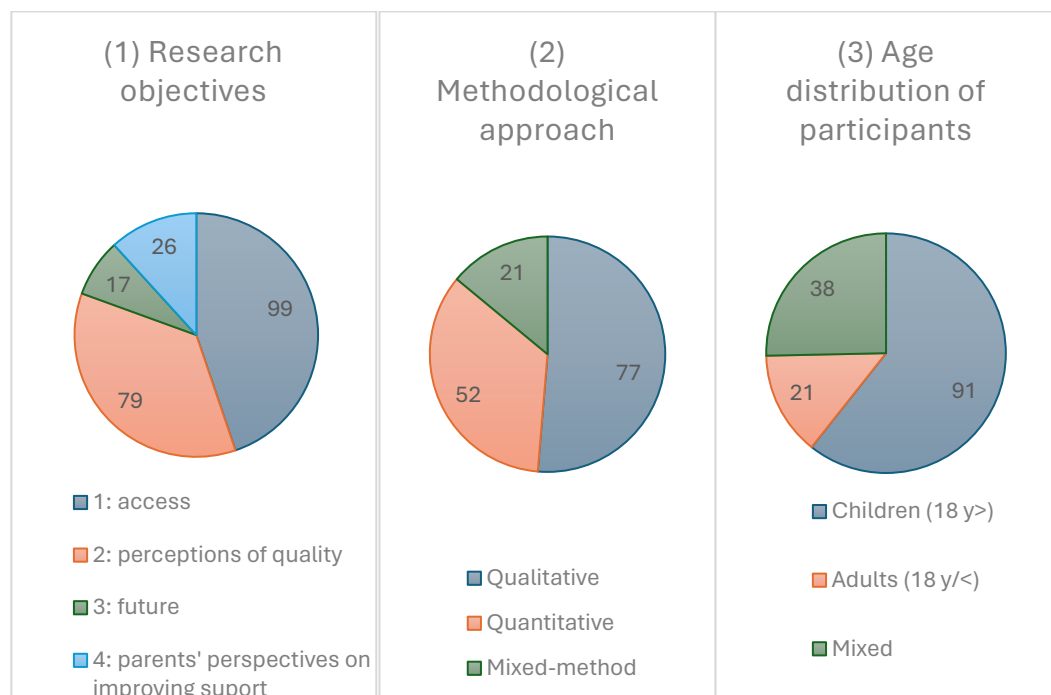


Figure 3. Breakdown of studies included in the systematic literature review by (1) research objectives, (2) methodological approach of the studies, and (3) age distribution of participants

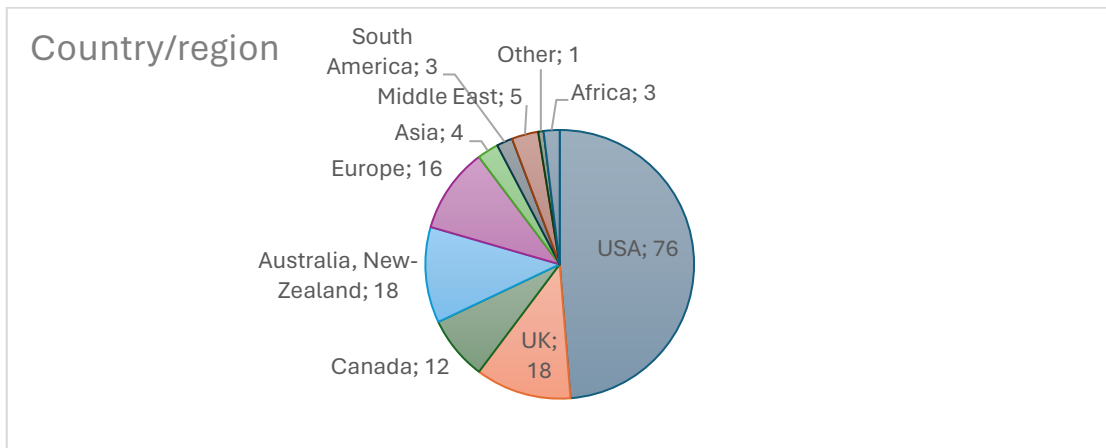


Figure 4. Breakdown of studies included in the systematic literature review by country/region

3.2. Main results

In the course of the analysis of the studies included in the literature review, a number of common points and connections between our research foci emerged, through which we developed a conceptual framework that serves as the basis for our empirical work (5. figure).

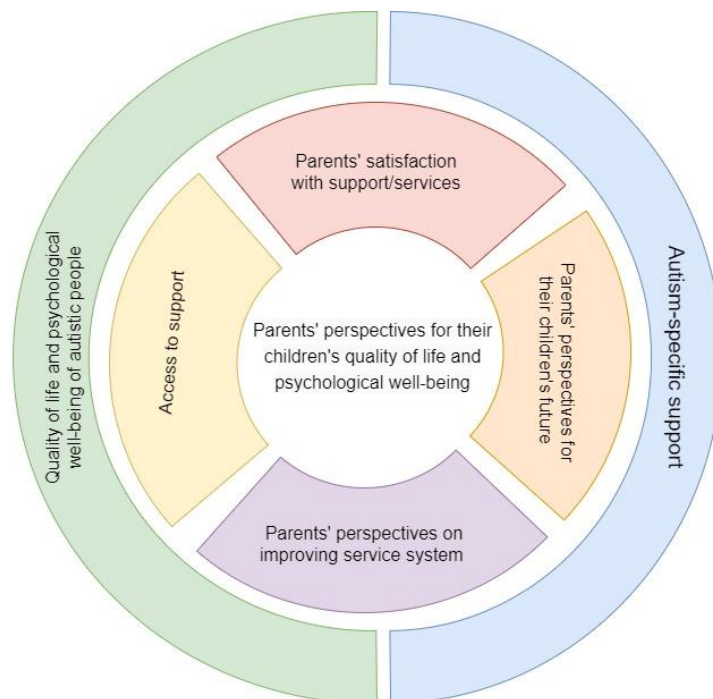


Figure 5. Summary diagram of the conceptual framework drawn up by the systematic literature review

The main aim of autism-specific support is to improve the quality of life and psychological well-being of autistic people and their environment (EMMI, 2020; Lord et al, 2020; Reed, 2016; Stefanik, 2018b). This fundamental aim and aspect has also clearly emerged as a central element of our own research focus.

(1) When parents are choosing a service for their autistic child, they try to make the best possible decision taking into account a number of individual factors. However, these considerations point in the same direction, with the overriding parental goal being that their child is safe and comfortable (Wilson et al, 2021a). At the same time, however, this is an extremely difficult process, which requires a great deal of effort on the part of families, mainly because of the scarcity of services, the spatial disparities in benefits and the difficulty of accessing reliable sources of information (Hermaszewska & Sin, 2021; Hoffman & Kirby, 2022; Kalash & Olson, 2012; Mackintosh et al, 2012; Marsack-Topolewski, 2020; Moodie-Dyer et al, 2014; Paula et al, 2020; Vasilevska Petrovska et al, 2022). In addition, there is no level playing field and access to support is influenced by the existing resources of families. Along the studies included, we see that a family with a higher socio-economic status (higher education, higher income), better advocacy skills, living near a larger city, has better chances when seeking autism-specific support for their child. (Baker et al, 2020; Florindez et al, 2019; Hamilton & Wilkinson, 2016; Lake et al, 2015; Lee et al, 2022; Marsack-Topolewski & Weisz, 2020; Nichols et al, 2019; O'Hare et al, 2021; Paula et al, 2020; Parry et al, 2021; Rausch & Pascoe, 2021; Sefotho & Onyishi, 2021; Smith-Young et al, 2020). Of course, all parents want to provide their child with support of a quality they consider appropriate, but in many cases, unfortunately, it is a challenge to get their child access to any kind of support at all (An et al, 2020; Ramachandran, 2020; Spiers, 2015). While we would have expected that differences between countries or states (for example, in the way service systems are structured) would have led to substantial differences in this issue, with a few exceptions (for example, the increased uncertainty of Latino families in the US about access to health care; Florindez et al, 2019), there are in fact no major cultural differences. This can perhaps be partly explained by the fact that the behavioral picture of autism also appears to be culture-independent (Freeth et al, 2014), so similar difficulties are faced in different parts of the world. However, it may be important to explore this aspect more systematically in later work.

(2) The quality of life and psychological well-being of autistic people is also a central element of the factors of satisfaction with support/services. We can look at this at a micro level, as it is essential for parents that their child's specific support is emotionally secure, e.g. surrounded by an inclusive community, with professionals providing autism-specific support focused on individual needs, including working in partnership with parents (Cremin et al, 2017; Cummins et al, 2020; de Verdier et al, 2020; Ghanouni & Seaker, 2022; Hoffman & Kirby, 2022; Stanford et al, 2020; Tamm et al, 2020; Walsh et

al, 2021). At the same time, at a macro level, transparency and access aspects of the service system are also an important part of parents' satisfaction with service/support (Bhat, 2021; Furar et al, 2022; Hermaszewska & Sin, 2021; Hodgetts et al, 2017; Lake et al, 2015; Montes et al, 2009; Pompa-Craven et al, 2022; Semigina & Stoliaryk, 2022; Stanford et al, 2020; Walsh et al, 2021; White et al, 2021). Families also feel more secure if they have reassuring perspectives and information about the service options that may be available in the future to ensure a good quality of life for their child. (Hermaszewska & Sin, 2021; Montes et al, 2009; Semigina & Stoliaryk, 2022; Stanford et al, 2020; Walsh et al, 2021).

(3) Parents' main goals and wishes for their children's future are also to see their children happy, successful and independent (Angell & Solomon, 2018; Finke et al, 2019; Starr & Foy, 2012). Parents see a key to this in the provision of an appropriate support system. One of the main concerns parents have about the future is what will happen to their autistic children if they are no longer able to support them (Benevides et al, 2016; Chamak & Bonniau, 2016; Finke et al, 2019; Kim et al, 2018; Marsack-Topolewski & Graves, 2020; Marsack-Topolewski & Weisz, 2020).

(4) The lack of adequate support is also strongly reflected in the parental suggestions. The starting point for these proposals is that there should be more and genuinely high-quality provision, for people of different ages and ability structures, in different settings (Abusukkar, 2019; Cheak-Zamora, Teti & First, 2015; Ghanouni & Seaker, 2022; Marsack-Topolewski, 2021; Sefotho & Onyishi, 2021; Song et al, 2022; Sosnowy et al, 2018; Vasilevska Petrovska et al, 2022). It would also be important to pay more attention to providing families with reliable information on the functioning of the service system and on specific benefits, as this is essential to facilitate access to service (Fleury & Chaxiong, 2020; Fong et al, 2022; Ghanouni & Seaker, 2022; Golnik et al, 2012; Hannah & Topping, 2013; Marsack-Topolewski, 2020; Serpentine et al, 2011). Parents also draw attention to the fact that increasing society's knowledge of autism is essential for their own and their children's quality of life, as it underpins the participation of autistic people and thus their quality of life and psychological well-being (Ghanouni & Seaker, 2022; Howell & Pierson, 2010; Paula et al, 2020).

4. EMPIRICAL STUDY

The doctoral research is embedded in a mixed methodological approach as part of the research phase 3/2 of the ‘Autism in Education’ Research Group of the Hungarian Academy of Sciences (HAS) – ELTE University (MASZK), which will run from 2016 to 2021. In the research phase 3/1 of the research series, the MASZK was the first in Hungary to carry out a nationwide, large-sample, quantitative research aimed at exploring the quality of life and psychological well-being of parents of autistic people (Eapen et al, 2023; MASZK, 2020; Volgyesi-Molnar et al, 2024). Building on this research phase, a qualitative methodological approach was used in phase 3/2 of the first phase to explore in depth the situation of families and their perspectives on service/support. The aim of the present doctoral research is to explore the subjective perspectives of parents of autistic school-age children and adults through a deeper understanding of the individual life stories that emerged in the interviews conducted in phase 3/2.

4.1. Objectives and research questions¹

1. An exploration of the service/support pathways of autistic children and adults based on parental accounts.
 - 1.1. What institutional and extra-institutional pathways preceded the current provision?
 - 1.2. What kind of in- and/or out-of-home care do autistic children/adults receive?
 - 1.3. What do parents mean by autism-specific support?
2. What supportive and barriers do parents of autistic children/adults perceive in accessing support for their children?
 - 2.1. Did they have the opportunity to make a real decision?
 - 2.2. What do parents perceive as supporting and impeding factors in accessing support/services?
 - 2.3. If they had the option to choose support, what factors influenced their choice?
3. How do parents judge the quality of support for their autistic child?
4. What are the visions for the future of parents who are raising autistic child / supporting autistic adult?
5. What suggestions do parents who have an autistic child/adult have for improving the support system?

¹ Due to the space limitations of the thesis booklet, the research questions 2.1, 2.2, 3 and 5 are discussed in the chapter "Results", and further results are also presented in the chapter "Discussion". Detailed results can be found in Chapter III of the PhD thesis.

4.2. Method

4.2.1. Ethical considerations

The research was carried out with the permission of the Scientific and Research Ethics Committee of the Bárczi Gusztáv Faculty of Special Education of Eötvös Loránd University (ethics permission number: KEB/2018/003). Due to the high sensitivity of the participants and the research topic, special attention was paid to ethical aspects at all stages of the study.

4.2.2. Participants

Participants were recruited from the first research phase of the MASZK research series. In this phase of the study, parents (529 parents of autistic children/adults) completed a questionnaire, at the end of which they were given the opportunity to indicate their intention to participate in an interview at a later stage (323 indicated this). A stratified random sample was used to select the participants. In total, 32 parents of autistic children/adults were interviewed. The participants in the present doctoral research included parents who were raising a school-age autistic child (n=10) or supporting an autistic adult (n=12), so a total of 22 parent interviews were analysed.

The focus of the interviews *with the parents (7 mothers, 3 fathers) of 10 school-age autistic children* are children (1 girls, 9 boys) aged 7-17. They all have a diagnosis of autism spectrum disorder, which they received between the ages of 2 and 10. Four of them have good intellectual and language skills, six have complex communication needs and were diagnosed with intellectual disability. Four families were classified as low or medium socio-economic status, and six families as high socio-economic status, according to the mother's education. Three families live in small towns, four in the capital and three in other cities.

The focus of the interviews *with the parents (11 mothers, 1 father) supporting 12 autistic adults* (1 female, 11 males) were young adults (aged between 20 and 34). All adults had an autism spectrum disorder diagnosis. With one exception (where the diagnosis was made at age 23), all had received an autism diagnosis in childhood (between the ages of 2 and 10). Six have good intellectual and language skills, six have complex communication needs and six have been diagnosed with intellectual disability. Based on the mother's education, six families were classified as low or medium socio-

economic status and six families as high socio-economic status. Two families live in small towns, four in the capital and six in other cities.

4.2.3. *Structure of the interview*

Semi-structured interviews were conducted with the participating parents based on the interview outline developed by the Research Team. The interview outline was based on literature research (e. g. Meirsschaut, Roeyers & Warreyn, 2010; Myers, Mackintosh & Goin-Kochel, 2009; Van Tongerloo et al, 2015) and the results of a large sample questionnaire carried out in the first research phase (MASZK, 2020; Stefanik et al, 2020; Volgyesi-Molnar, 2024). In designing the interview setting and drafting the interview outline, we drew heavily on the recommendations of Cridland et al (2015).

In order to develop the final content and format of the interview, four pilot interviews were conducted with parents of autistic children who did not participate in the subsequent data collection. Based on the experience of the pilot interviews, some minor modifications were made to the interview outline and inclusion criteria.

The semi-structured, questionnaire-based interview consisted of five main parts: (1) 'Introduction, greeting and introduction', (2) 'Background and current situation', which explored the current social context of the participating parent and family. (3) 'Exploratory-qualitative section', which included topics on the current situation and life history of the parent's autistic child, the parent's personal life history and the expected future, followed by (4) 'Choice of institution and institutional education' and (5) 'The parent's current situation and life history'. (5) In the concluding part, parents were given the opportunity to ask any questions they considered important and the interviewer informed them about the MASZK research.

4.2.4. *The framework of the interview*

The duration of the parent interviews analysed in the present study was approximately 2 hours (shortest: 71 minutes, longest: 163 minutes; mean: 114.9 minutes). To avoid overburdening parents, the interview could be interrupted with a break. The interviews were conducted in a quiet and calm place, suitable for independent but two-person interviews, as close as possible to the parents' needs and place of residence. The locations were organised with the help of key teachers working in the MASZK throughout the country. The interviews took place between April and June 2018. The interviews were recorded on digital dictaphones, and using the recorded audio material, verbatim electronic transcripts of the full interviews were produced by two typists.

4.2.5. Analysis of the interviews

In our study, the analysis of the parenting narratives was conducted in an exploratory manner, with two preparatory phases, supplemented by thematic analysis, along the lines of the constructs operationalising the research questions (Braun & Clarke, 2006; Terry et al, 2017).

Prior to the thematic analysis of the interviews, we prepared the interview texts in two phases (in excel) and then used ATLAS.ti text analysis software (Atlas.ti version 8) in the process of thematic analysis. The complete process of the analysis is presented in *Figure 6*.

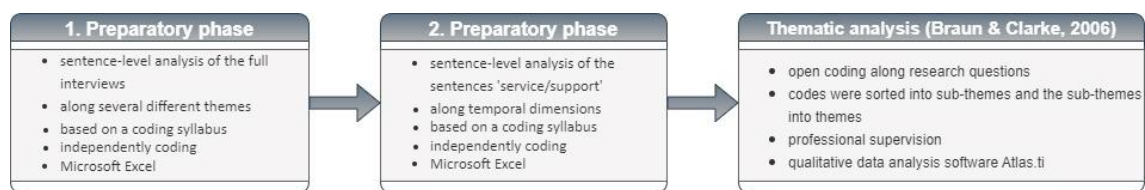


Figure 6. Interview analysis process

The first preparatory phase

After an initial read-through of the interview transcripts, a sentence-level analysis of the full interviews was conducted, along several different themes (e.g. parent, child, family, service/support, other people and places), based on a coding syllabus. Of the 22 parent interviews, 12 interviews were coded independently by another member of the research team, continuously checking for inter-rater agreement (average agreement between the two coders: 93.88%).

The second preparatory phase

In the second preparatory phase, only those sentences of the interviews were included that were coded as 'service/support' in the large thematic grouping in the first phase. The aim was to identify and explore the different forms of support and service for autistic children, adults and their parents along temporal dimensions. The preparation was carried out along a coding syllabus. In the second preparatory phase, independent coding was also applied to 10 interviews, checking inter-rater agreement (average agreement between two coders: 72.21%).

Thematic analysis

Following the preparatory phases, we followed the steps and aspects of thematic analysis developed by Braun and Clarke (2006). In this analysis phase, the qualitative data analysis software Atlas.ti was used.

In the *first step*, we coded the relevant parts of the interviews according to the focus defined by our research questions. If a given narrative contains information on more than one thematic category, it can be coded within several categories. In the *second step*, we organized the resulting codes into sub-themes and the sub-themes into themes. For each sub-theme, we assigned how many participants and how many narratives within the interviews they were mentioned. In the *third step*, charts and tables were created to visually represent the topic hierarchies per research question. In order to increase reliability, all codes were discussed and revised several times in regular consultations during the thematic analysis phase until final consensus was reached. Decisions and decision criteria were documented (Lincoln & Guba, 1985).

4.3. Main results²

In presenting our findings, we will focus mainly on the deeper, broader perspectives and contexts that emerge from the interviews, which we will present illustrated with interview excerpts, in addition to the thematic hierarchy developed in the thematic analysis.

4.3.1. What supportive factors and impeding factors do parents of autistic children/adults perceive in accessing supports/services for their children?

4.3.1.1. Was it possible to make a real decision?

In the 22 interviews, parents reported a total of 68 situations where a decision related to the support of their child could be made. In the thematic analysis of these situations, three themes emerged along the family's perspectives on the decision: (1) situations where the parent judged that they had at least two service options available and considered appropriate for them were considered as *real decisions*. We also included situations in which there was a choice to claim a particular benefit. We have treated as a subset of a real decision the *situation of choice* (2), i.e. when parents judged that they had at least two service options available and considered appropriate for them to choose from. Furthermore, we defined as (3) *not a real choice* those situations in which parents judged

² Only the main results of research questions 2.1, 2.2, 3 and 5 are discussed, the rest can be found in chapter III of the PhD thesis.

that they had only one available and/or suitable option or none at all. This included situations that parents described as 'time-wasting', i.e. where they decided to opt for a support/service only because it was important for their child to receive some support, but where there were no real decision factors behind this. Not real decision situations are those in which the child/adult ended the support without their own or their parents' involvement, or against their will.

Out of the 68 decision situations that emerged from the interviews, 30 situations were identified along the lines of the above factors in which parents experienced that they had no real choice. While there were 38 situations where parents had a real choice, only 15 of these were identified in the interviews (e.g.. 23 situations where parents had the choice, for example, of whether to use a service, but not the choice of more than one service/support).

Parents of autistic adults seem to experience more often than parents of school-age children that they had no real choice about supporting their child. Looking at the socio-economic status of families, we see that both low/medium and high SES families identify both non-genuine, genuine decision and choice situations, but the number of choice situations is almost twice as high in high SES families. In terms of where families live, we see that although situations of no real choice for parents were found among families living in small towns, cities and the capital, this is particularly marked among parents living in non-metropolitan areas. Most parents living in the capital identified at least one situation regarding support for their child where they had a real choice. Interestingly, the proportion of parents living in small towns is very similar, with all but one parent reporting a situation of real choice. When looking at the classification of decision situations by type of support, we see that parents felt the most likely to have a real choice was in the case of support outside the institution (e.g. private sector). It is important to underline that inactive periods at home for autistic adults, with one exception - when the young person quit his/her job - cannot be identified as a real decision in all other situations.

4.3.1.2. What do parents perceive as supporting and impeding factors in access?

Barriers and/or facilitators to accessing support/service are identified in all parent interviews. A total of six themes emerged, which may include relevant sub-themes on both the barrier and support sides (6. figure).

The most prominent factor seems to be the *availability of service*, which is also linked to the other themes. One of the most prominent sub-themes is the lack of autism-

specific support and benefits. There is a marked parental experience that there are even fewer support options for autistic adults, so they are often left out of the service system. It is also common for there to be no or very few support options close to where families live, particularly for families living further away from the capital. One rural parent said: *"There is only one autism school far away, it was not a matter of choice, we were lucky to be accepted."* (P15_23). Parents' narratives revealed that they often encounter resistance from institutions and managers when accessing institutional service. Parents in these situations often felt powerless and often experienced what one parent put it like this: *„Heaven and earth is what is written down and what is... what should be and what is..."* (P6_9).

However, systemic supports are also identified as a sub-theme related to access to service among the supporting factors. This can be the case when parents have a foreseeable perspective that institutions build on each other (e.g. support is available from kindergarten to adulthood in the same institution). This can be a safe point and make planning easier for families: *„I've never had to worry because I've always known that one institution builds on another"* (P19_23). It is also a systemic support that a diagnosis of autism gives extra points for university admission, which helps with entry to higher education. Similarly, internship programmes can help in gaining paid employment. Unfortunately, however, in the absence of additional autism-specific support, these opportunities have not been a long-term success, with adults dropping out of support within a few months.

Among the supporting factors related to *accessing information* about *benefits*, some interviews revealed systemic supports such as attendance at open days, trial days and support from professionals, but the most striking parent experience was that it requires a huge investment of parental energy to gather information about benefits. Parents see one of the main reasons for this as being that there is little and sometimes inaccurate and misleading information available, both at a systemic level and about a specific support option. As one parent put it, *„the main experience is just coming up against brick walls, and if you want to be sure, you have to do it yourself [information gathering]."* (P12_26). However, parents felt it was a supportive factor when they had the opportunity to get reliable information from professionals.

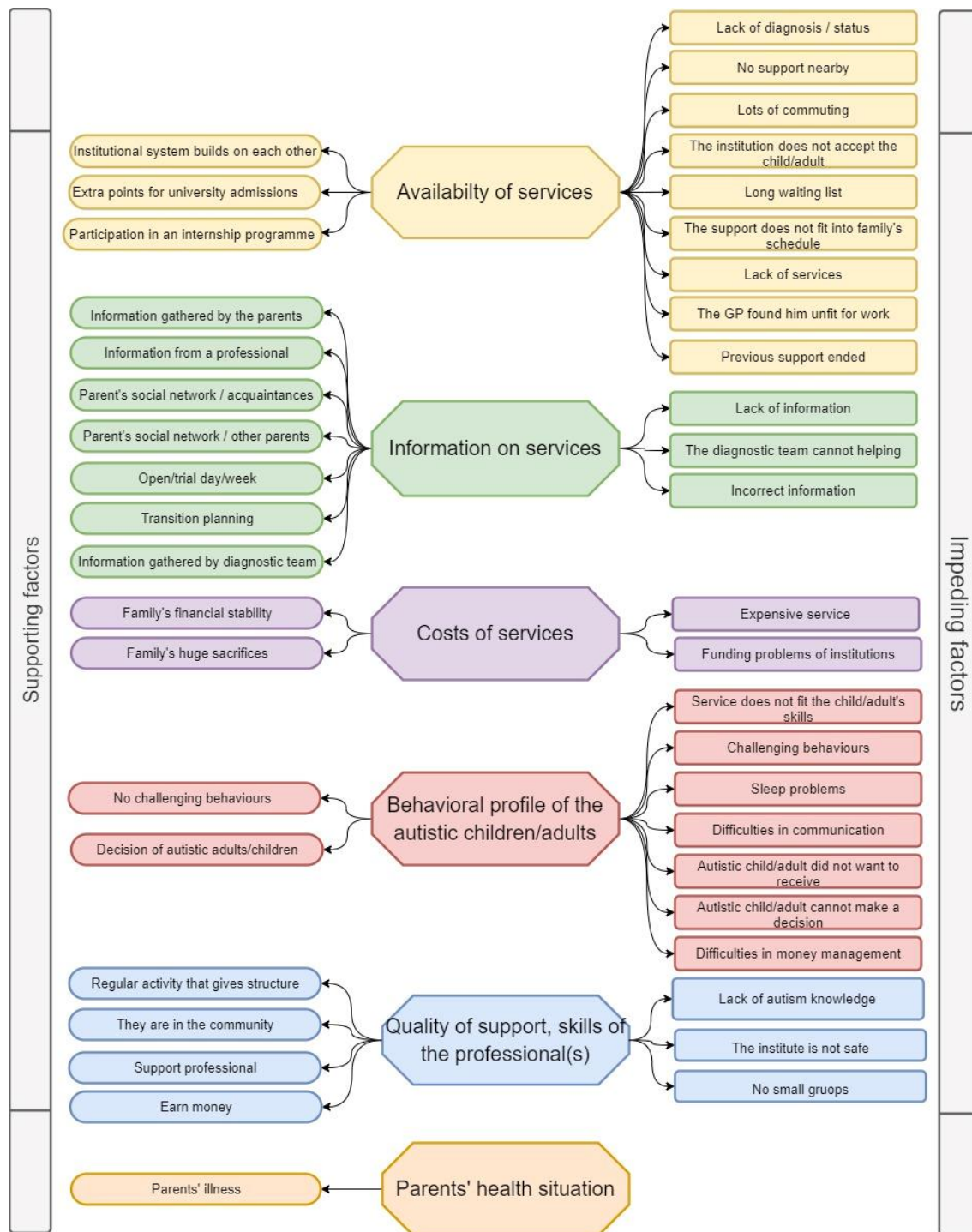


Figure 8. Factors supporting and impeding access to support/service for autistic school-age children and adults

Parents' narratives also expressed that access to support is determined by the *cost of service and the financial stability of the family*. Related to this, 6 parents reported that their families make huge sacrifices specifically to be able to finance the cost of private sector support for their child. It is shocking that if the family cannot financially afford to fund the costs of support, the options for families are radically reduced and even the autistic child/adult may be left without support. One mother, for example, said of residential institutions: „well, these are kind of horrible prices, but even so, waiting lists

go up to hundreds-long, meaning years...” (P19_23). Another barrier was the funding problems of institutions, which for example prevent them from providing autism-specific support. „Well, services, autism-specific support, that would be very, very good, that is what we are peddling, but we have not won the bloody tender we wanted.” (P17_34).

The behavioral profile of the child/adult also appears to be a determinant of access to support. Several parents commented that the support options available do not match their child's needs. It is also very striking that children/adults whose autism-related difficulties manifest themselves more often in the form of challenging (typically externalising) behaviors are often excluded from support, whereas, for example, children/adults who compensate well in institutions and who cooperate more easily have access to support. „There are children who shout all the time, so the speech therapist doesn't like them, won't take them on. But [my son] is a quiet child and the speech therapist was happy to take him.” (P5_12).

The most common perspective was that families chose the support because it provides their child with some regular activity that gives structure to their life, and at least they are in the community or have a support professional with them.

4.3.2. How do parents rate the quality of support for their autistic child?

Along the factors of parents' satisfaction and quality perception of their child's support, 6 themes and related sub-themes and sub-themes emerged, along which parents' perception of support can be positive or negative.

One of the most prominent factors seems to be *cooperation and communication*, with 5 sub-themes. Parents seem to have a more positive perception of the whole support process if they perceive the cooperation with professionals as effective, partner-like and smooth: *„(...) I am not an external observer of my child's life, but an active participant, and it makes a very big qualitative difference. So that I as a parent, every day, if I ask, I don't know what day my child had, what he did, did he participate, did he not participate, did he eat, did he run, did he cry, did he laugh, everything and I get this information every day.” (P8_8).*

It seems obvious that parents think it is important that their children's *everyday lives* are *safe, happy and active*. In terms of *personal environment*, the main parental concern is that their child is surrounded by a truly inclusive and participatory environment, for example, having the opportunity to meet neurotypical people, not being a victim of peer abuse or bullying. It is also important for parents that their child's daily life is filled with meaningful, regular and active activities. One mother mentioned the following as a

positive aspect of her daughter's day care centre. „Well, they really keep all his time engaged, there is no idle time to be just sitting and staring, they keep them moving, exercising, running, doing aerobic activities, making music, doing housework, handicrafts, and there is even developmental intervention” (P11_23).

The sub-theme unit on methodological elements related to *expectations of professional work* is linked to several sub-themes that also appear in the elements of autism-specific support, such as the existence of an individual development plan based on individualised assessment, the importance of transition planning, or the use of autism-specific tools and methods. But the most prominent aspect is whether the support is tailored to their child's individual needs and abilities. Under the sub-theme of the main aims and focuses of professional work, one of the main aspects of quality assessment of parents appears: whether their child is making progress, especially in the areas of socio-communication, independence and independent living, and whether they are receiving real help in managing their child's challenging behaviors.

On the topic of *expectations of staff*, the most prominent are expectations of the attitude and personality of professionals and the quality of the relationship between their child and the professional. Conversely, less prominent, but appearing in the satisfaction aspects, are whether professionals are trained, competent and prepared. However, whether there are enough professionals and whether their child receives sufficient individual attention is also of major importance.

The sub-themes and sub-themes related to the theme of *practical expectations* actually overlap with the other themes (especially the theme of safe, happy and active everyday life). Parents do not talk about the aesthetic design of the buildings where they provide support or the quality of the furnishings, but rather about whether the environment is safe and functional for their children. Practical aspects of the functioning of the support also focus on whether the support/service is safe for children and their families, for example, whether the number of groups is adequate or whether there is the possibility of full-day supervision in the institution so that parents can work.

The issue of *access to services and information* also appears among the factors that influence parents' perception of quality. Parents are positive about the existence of benefits and discounts related to autism diagnosis, but unfortunately they feel that the amount and extent of these benefits are not sufficient. Another important factor is how easy it is to find out about the different support options, how easy it is for families to access them and how complicated it is to understand the administrative process to access them.

4.3.3. What suggestions do parents who have an autistic child/adult have for improving the service system?

Parental suggestions in the interview narratives cluster around six themes, but the emphasis on these themes is very uneven across the interviews.

The main theme that stands out most prominently among the parent suggestions is *more autism-specific support*. Aspects adapted to the autism spectrum, different ages, ability structures and settings emerged in the parent narratives. For example, more comprehensive aspects: expanding the range of support options available nationally and free of charge, while at the same time accessing more autism-specific support professionals.

In relation to the age perspective, there is more parental demand for more support/services available, from reliable diagnostics and early development, through primary and secondary school support, to adulthood: *„I would like to see an institution that takes you through from the tiny baby stage to the young adult stage, without parents or background, and leaves them in life without having to worry about what happens.”* (P15_23). Parents reported a particular gap in support for autistic children in mainstream schools. It would be important to increase the autism literacy of teachers in mainstream schools, and to support the wider presence of autism-trained professionals (e.g. specialised teachers of autism spectrum pedagogy) in mainstream institutions. However, most of the parent suggestions focus on one of the biggest areas of shortfall: more support for adults. There is a strong parental demand for improving the capacity of the health care system to provide autism-specific support, in general in all areas of health care, and in particular in dentistry, pulmonary care, psychiatric care and various screening tests.

Two sub-themes related to the *improvement of the social benefits system* stood out. In addition to increasing the amount of social benefits, simplifying and making the necessary administration more transparent would help autistic people and their families.

In only six narratives was the need for more attention to be paid to *supporting parents*. One possible reason for this may be that parents no longer dare to think about their own support needs in the struggle to support their children, as one parent put it. (...) *„I know how immeasurably short there are of professionals and I know how immensely overwhelmed they are. And I didn't feel, I thought, that my soul was a secondary thing compared to what they have to deal with the children in the first place and we are a mass of mothers who want this [support], but I just thought that I couldn't burden anyone else with it, but I should have.”* (P18_26). In some of the interviews, the need to provide more

support for parents so that they have more time for recreation, leisure and work was raised. One important means of doing this would be, for example, to have more and more easily accessible opportunities to get help with the day-to-day supervision of an autistic child or adult.

A prominent theme is the role of *assistance in accessing services*, with the most common theme being more and more easily accessible information about support options. It would make it easier for parents to make decisions about benefits if, for example, the websites of educational institutions were up-to-date and easy to navigate. It would also be helpful if information on autism-specific support could be easily accessible and found in one place in an authoritative way.

5. DISCUSSION

Most of the findings of our own empirical study are in line with the international research history included in the systematic literature review. It is exciting that there is a significant overlap between the results of our own empirical study for Hungary and the results of the 150 international studies analysed in the systematic literature review. It seems that whatever country, region or culture the studies were conducted in, similar factors emerge in the perspectives of parents of autistic children/adults on their child's opportunities. However, we see differences in emphasis, which are discussed in detail in this chapter.

The journey of autistic people in the service/support system

Similar to national (MASZK, 2020; Stefanik et al, 2020; Volgyesi-Molnar et al, 2024) and international research (Hoffman & Kirby, 2022; Marsack-Topolewski, 2021; Marsack-Topolewski & Weisz, 2020; Walsh et al, 2021), our own empirical study has shown that as adults age, the amount of support available decreases, and autistic adults may be excluded from the service system for months or years. There is a 'gap' in support after leaving public education, with some parents trying to keep their child in the school system as long as possible. In addition, we also see that parents often find that autism-specific support is not available within the school system. As a consequence, more families are either opting for private schooling (e.g. An et al, 2020) or for autism-specific or complementary or alternative therapies in private service, as is the case internationally.

Parents' fight for access to support for their autistic children

Although scientific evidence shows that autism-specific support is the main tool for improving the quality of life of autistic people and their families támogatás (EMMI, 2020; Lord et al, 2020; Reed, 2016; Stefanik, 2018b), in many cases parents feel that accessing support for their children is an ongoing struggle, regardless of age, ability structure or place of residence. Families' own resources are a key factor in determining which aspects to consider when assessing support options in the first place. Hungarian parents' experience of having no real choice about how to support their child is consistent with international findings (An et, 2020; Ramachandran, 2020). It is clear from the Hungarian sample, and the international results also show (Mackintosh et al, 2012; Richardson et al, 2022), that one of the main parental concerns when seeking support for autistic children/adults is that their child should feel well, but the limited support options, long waiting lists and the risk of complete inactivity in adulthood mean that parents are

generally only able to focus on the main goal of finding some kind of provision for their child (Fong et al, 2022; Hermaszewska & Sin, 2021; Hoffman & Kirby, 2022; Paula et al, 2020; Vasilevska Petrovska et al, 2022). At the same time, access to support/services is further complicated by the fact that in many cases it is a huge challenge for parents to obtain reliable information, and it is difficult to choose from the wealth of information available to select the most relevant and effective interventions for their child.

Parents often feel that accessing support is a lonely, fruitless struggle (e.g. Loukisas & Papoudi, 2016), and that in many cases they attribute any success solely to their own investment of energy, luck and personal connections. Both nationally and internationally, the psychological well-being of parents often takes a back seat in organising support for their children (e.g. Davy et al, 2022). While they devote all their energies to fighting for access to support for their child, they often fail to seek help and support for themselves, even when they really need it.

Parents' views on the quality of support for their autistic child

In our own study, as in the international literature (Ramachandran, 2020; Stanford et al, 2020; Tamm et al, 2020), one of the most prominent themes is the *quantity and quality of cooperation and communication between parents and professionals*. Partnership and communication is one of the keys to parents' trust in the professionals working in support.

It's natural that parents are keen to keep *their children happy, active and safe every day*. As in the international literature (e.g. Cummins et al, 2020; de Verdier et al, 2020; Vasilevska Petrovska et al, 2022), the most striking aspect of parents' perceptions of professional work is *whether the support is truly individualised and whether the child/adult's development is noticeable*. In relation to the target areas of support, it should be highlighted that parents mainly mentioned the areas of socio-communication and independence, as well as the management of challenging behaviors, which are classic target areas for autism-specific support (EMMI, 2020; Stefanik, 2018b).

The role of professionals is crucial in how parents assess the quality of support. Based on our own research, it seems that *although more parents emphasise the importance of the professional's training and expertise, the professional's attitude and personality appear to be more prominent factors*. There also seems to be a similar correlation in the area of practical expectations of support/services, with *parents almost exclusively mentioning very basic aspects that can strongly determine the quality of life of their child and family*.

Overall, we can see that Hungarian parents – in line with the international literature (e.g. Cummins et al, 2020; Sosnowy et al, 2018; Vasilevska Petrovska et al, 2022) – judge the quality of support for their children on the basis of whether it is appropriate to their individual abilities and needs, and whether it ensures their quality of life and psychological well-being. We find that families find it so difficult to access the right quality of support that in this struggle they have no real opportunity to consider deeper issues, and often do not dare to think about them.

Parents' suggestions for improving the support system

The most prominent key theme is to *increase the number and improve the quality of supports/services available to autistic children/adults* - at all ages and ability structures, but with a particular focus on co-education, secondary school and adulthood. This would also mean that Hungarian parents would not be left alone in the struggle to support their child, and could therefore see a more secure future for their child. This link is also reflected in the international results (Finke et al, 2019; Marsack-Topolewski & Graves, 2020; Sosnowy et al, 2018). Our systematic review of the literature also found that parents are pressing for more support for their autistic children (Abusukkar, 2019; Marsack-Topolewski, 2021; Marsack-Topolewski & Weisz, 2020; Song et al, 2022; Walsh et al, 2021), but this aspect seems to be so prominent for Hungarian parents that other factors were much less prominent. Against this background, and along the lines of our findings related to our previous research questions, we assume that for the majority of parents in our study, access to adequate quality support for their children in everyday life, and support that is available to the family - both physically and financially - is such a huge problem that they are less likely to raise other aspects, if at all. The organisation of regular and systemic support in everyday life and concerns about the future therefore lead parents to focus primarily on the availability of support/services for their children in the present and in the future.

Less prominent compared to international results (Ghanouni & Seaker, 2022; Howell & Pierson, 2010; Paula et al, 2020), but also present in our own results, is the *aspect of social acceptance of autistic people, which could be achieved more and more mainly by improving the knowledge of autism in society*. An interesting finding is that while in the international research findings parents mostly emphasise the importance of obtaining transparent, easily accessible information at the system level (Farley et al, 2022; Ghanouni & Seaker, 2022; Hodgetts et al, 2017), our own results also show that legal assistance may be needed in a support system that is difficult to understand. The findings

suggest that *parents are less likely to think that they themselves, as competent decision-makers, could access reliable information about their child's access to support*, or that they could be provided with a transparent service system in which they would have little or no reliance on their personal relationships or legal assistance. While parents' own support needs are typically neglected, it is welcome that the need for *parents raising/supporting autistic children to be able to access support directly* is also mentioned in the parenting perspective, albeit much less frequently.

Limitations of our studies

Our study was structured in two parts - a systematic literature review and an empirical study. In assessing our results, we must take into account the limitations of the studies. The main limitations in the *systematic literature review* are: language (we only used English language publications), and the quality of the research methodology of the studies was not assessed in the selection process. The main limitations *in our empirical study*: we reached fewer families with low socio-economic status, the majority of the interviews were conducted with mothers, we assumed all information from parents to be true (e.g. we did not check their child's autism diagnosis), there may be recall bias in the interviews.

Outlook

The aim of the doctoral dissertation is to understand the perspective of parents of autistic children/adults, but for us, as committed advocates of the "Nothing about us, without us!" principle³, one of the most important additional goals is to give voice to autistic people (e.g. Ghanouni & Raphael, 2022; Walsh et al, 2021).

We are confident that the results of our research can contribute to improving the support for autistic people, the support system and thus the quality of life and psychological well-being of autistic people and their families by integrating parental perspectives. The task and responsibility is shared, remember the message of parenting: *they are living people, it is not just fiction*" (P15_23).

³ see for example: the UN Convention on the Rights of Persons with Disabilities (ratified by Hungary with Act XCII of 2007)

6. THE AUTHOR'S MOST IMPORTANT PUBLICATIONS

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The full publication list is available on the Hungarian Scientific Bibliography (ID: 10069455).

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