

A case study research on perception and attitudes of parents of adolescents with Autism Spectrum Disorder regarding the language teaching of their children

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Abstract

Autism spectrum disorder (ASD) as a lifelong neurodevelopmental disorder puts a significant strain on the family. During secondary education, when the brain is rewired, language learning becomes a challenge for ASD students and their parents. Using this as a foundation, this article's main objective is to know the opinions and attitudes that characterize the parents of adolescents with ASD regarding the teaching of the Greek language to their children. Through a descriptive qualitative study, with a semi-structured interview of 32 items (n=30 parents) and an in-depth analysis, this goal has been accomplished. The main conclusion that has been reached is that participants-parents applaud their own assistance in the educational process, claiming though for special education teachers' cooperation, support from the Greek State and availability of specialized staff and resources to carry out smoothly the language learning process, with the aim of optimal outcomes in the linguistic competencies for their ASD adolescents.

Keywords: Autism Spectrum Disorders, Teaching of the Greek language, Adolescents, Special Education Teachers, Parents.

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder with central symptoms, the reduced social interaction and communication, the presence of limited interests and recurrent behaviors, and has a lifelong impact on the life of the individual (Masi et al., 2017). According to APA (2013) the DSM-V classifies individuals with ASD in severity levels, depending on their need for support (need a lot of substantial support, need substantial support and need support), while ASD diagnosis is based on a pattern of impairments in two broad domains of behavior, characterized by extreme heterogeneity in symptom expression: a) Impaired social interaction and social communication and 2) Restricted, repetitive behaviors or interests (Kanner & Asperger, 2016). The present study does not focus on the severity levels of the ASD adolescents' need for support, as the children of the participating parents belong indiscriminately to all three categories, with diverse heterogeneity in the appearance of symptoms.

The etiology of ASD remains a topic under discussion and is sought in psychological, sociological and biological factors (Nadesan, 2020). Since ASD cannot be eliminated, it necessitates a constant support of the individual and his family throughout his life (Sussman et al., 2015). Often, education and support of people with ASD have the effect of mitigation of symptoms or even of improving behaviors. However, people with autism remain in the spectrum and in their adult life, while still experiencing difficulties in independent living, in their professional rehabilitation and in their mental health (Lord et al., 2020).

The upbringing of a child with ASD is a significant aggravating factor for the family (Smith & Anderson, 2014). Most researches have focused on the recording of the psycho-emotional difficulties of parents of children with ASD, while recent studies have examined the

effectiveness of psycho-educational programs for parents, focusing on individual factors, such as improving the symptoms of ASD in the child and increasing the parent's participation in the programs (Beaudoin et al., 2019).

Until this date, there is little research worldwide and in Greece that studies the difficulties encountered by parents of adolescents with ASD in relation to the educational process. The existing shortage justifies the relevance of this research (Sproston et al., 2017).

Family and ASD adolescents

Adolescence is for the western civilization a critical developmental stage, with special importance (Goodway et al., 2019). For children of typical development it is a period full of creativity, during which autonomy of the individual is developed. In contrast, the family of the person with ASD, while being a spectator of a normal physical development, also notices that the child is unable to fight for its independence. Although the child with ASD can acquire many and important skills through proper training, remains completely different from its' peers and requires continued monitoring on basic self-service areas (Samara & Ioannidi, 2019).

This situation makes clear the permanence of disability for parents (Jinks, 2019). They are now completely aware of their child's ever-dependency on them and have the unwavering sense of responsibility that will last for all of their life (Chen et al., 2019). The transitional changes, physical and psychological, to adolescence for a child with ASD cannot be perceived and the greater burden falls in the family (Burke et al., 2019). The needs of the adolescent and of the family create a reality that requires a careful planning and emotional acceptance, from the parents themselves.

Parents are still engaged with the suitable structure for their adolescent's education, yet it begins to be suggested the necessity of planning for the transition into adulthood. Their aim is their adolescent's inclusion in society and they seek understanding of their feelings from experts, relatives, friends, colleagues and society; support from specialists; not to feel helpless and to be able to protect all family members without exception; to be recognized for them the right to live (Finke et al., 2019).

Teaching of Greek language to ASD adolescents

Teaching of the Greek language at the Curriculum of General Education is directly related to communication, as it is based on the communicative approach that relies on meaning rather than form (Mitsis, 2015). Regarding the education of students with ASD, one of the primary objectives is the understanding of the meaning of communication, as well as the use of communication skills in different social contexts (Parish-Morris et al., 2019; Muskett, 2016).

The acquisition of reading and writing has communicative character, but the teaching of the language is separated from the oral speech, which many students with ASD don't possess and possibly will never acquire it. The cultivation of oral speech is included in the communication skills (Bak et al., 2019). It is noted that in the Curriculum of the Greek language remains as a goal the acquisition of phonemic awareness and the conquest of the mechanism of reading, which is based on graphic and phonic correspondence, wherever this is possible to occur (Georgali, 2017). However, the main objective of the Curriculum for students with ASD is the visual recognition of words or symbols, as an alternative way of learning and using the written word (Georgali, 2017).

Students with ASD belong to a wide range of differentiated skills. Therefore, they should also be offered a variety of writing approaches, such as the voice method and the visual recognition of words or symbols. Through elementary school some capable students with ASD, like the ones with Asperger's syndrome, may appear as if they have only specific learning disabilities, such as reading or language processing. But, as they enter high school, with its' higher social and communicative requirements, and as adolescence begins to rewire the brain, ASD reasserts its social communication difficulties, due to the higher levels of cognitive demand (Crothers et al., 2020). Generally, special emphasis is put on the visualized

presentation of activities, since in ASD students the visual channel is the predominant channel of pulse acquisition and processing (Kotsi & Fernández Robles, 2023; Kakouros & Maniadaki, 2015).

Methodology

In this interpretive qualitative study, a case study design was used. When the research interest is transferred to a specific, complex and functional situation, then the concept of Case Study is used to characterize the research strategy (Yin, 2017).

Necessity and usefulness of the educational research

This educational research contributes significantly to the development of the relevant educational scientific fields, as the use of its findings can lead to its further application both by the State itself as an educational policy, as well as by the teachers and the parents of adolescents with ASD. In reality, and given the very limited research activity in this specific area the usefulness of the current research is even bigger.

Research questions

In the present article a specific number of questions are presented, since the attention is focused on revealing these exact results. The study sought to determine specifically the opinions and attitudes that characterize parents of adolescents with ASD, regarding the teaching of the Greek language to their children. Subsequently, the following sub-themes emerge with their corresponding 16 questions:

- Family context factors that promote and prevent language learning in adolescents with ASD (mutual cooperation among family members, means of communication with the ASD adolescent and strategies applied, existence of a language program inside home, cooperation with the school context).
- Detection of the pedagogical needs and demands emerged from parents of adolescents with ASD (assistance from special education teachers for the adolescent's teaching, difficulties in adolescent's response to language learning, obstacles because of the working life, what pedagogical help is required).
- Value the role of the educational program within home (achievement of educational objectives set by special education teachers, language improvement of ASD adolescents, modifications in the family program and tools used inside home, effectiveness and improvements of the implemented educational program inside home).

Research design and data analysis

For the development of the research a semi-structured interview was created, as a research tool, designed to address a wide range of questions that ask why, what and how of the issue proposed and leading to exploration, explanation, description, evaluation and theorization in context (Harrison et al., 2017; Yin, 2017). After the initial design of the instrument and before its application, issues of relevance and clarity were examined. Thirteen experts on the fields of ASD, special education, and teaching validated the interview guide with these exact criteria being assessed. The numbers were estimated by using the Aiken V formula, frequently applied in educational research, such as Muliana's et al. (2020) and Ramadhan's et al. (2019), in order to calculate the content-validity coefficient of the items-questions of the instrument, based on the results of the experts' assessment (Aiken, 1985); the results showed a range between 0,92 - 1,00 for both criteria, according to experts' judgment.

Table 1. Aiken’s V values

Semi-structured Interview Item	Aiken’s V	
	<i>Relevance</i>	<i>Clarity</i>
6. Is there a mutual cooperation among family members (spouse, siblings, grandparents, etc.) regarding the communication with the autistic child?	0,98	0,98
7. If a member of the family is not willing to cooperate in the language learning of the child, what are your reactions to solve the problem?	0,98	0,97
8. What means of communication do you use with your autistic child?	0,98	0,98
9. Are you able to organize an everyday language learning program inside home, with all members taking part in it? How feasible is this?	0,98	0,98
10. Is it possible to follow at home the pedagogical directions given from the school context?	1	1
11. Do you have strategies at home for working with your child? What difficulties do you encounter in the language teaching of your child? How do you think they could be solved?	0,98	0,92
12. Do you receive help from special education teachers, in order to guide your child’s teaching? Is there collaboration between special education teachers and parents at home?	0,97	0,95
13. What difficulties do you encounter in child’s effort to respond to language learning?	0,98	0,98
14. If you, because of your working life, cannot apply educational techniques on your autistic child, what help would you need to facilitate the child’s progress?	0,98	0,98
15. What kind of pedagogical help would you appreciate, according to the needs of your autistic child? What information and training do you need to educate your child?	0,98	0,97
16. Are the educational objectives set by special education teachers achieved? Do you offer your collaboration inside home?	0,98	0,97
17. Does your child with your cooperation show signs of language improvement?	1	1
18. How is work done and promoted within the home?	1	1
19. In which ways have you modified your family program to facilitate your child’s language abilities?	1	1
20. What tools do you have at your disposal and which have you received to promote the educational program within the home?	1	1
21. Do you think the program you follow at home is effective? What improvements do you think could be made? What further difficulties appear in implementing the educational program within home?	0,95	0,92

The first sector of the semi-structured interview included seven questions of demographic interest, while the second one about the opinions and attitudes that characterize parents of

adolescents with ASD, regarding the teaching of the Greek language to their children consisted of sixteen questions, which were open.

The analysis of the data was qualitative, with the descriptive method used, providing the exact description of the phenomenon under consideration (Schratz, 2020; Mantoglou, 2015).

Sample and data collection

The type of sampling in this educational research is intentional, meaning that it involves selecting only a sample of people from the study population. Qualitative research typically uses *purposeful* sampling, as it does not seek to measure issues, make population level statements or extrapolate findings (Hennink et al., 2020).

The population participating in the study is a group of parents with ASD adolescents (belonging to charity non-profit organizations for parents and friends of autistic people with representation in Northern and Central Greece), with n=30, of which 70% were women. Their ages were from 39-62 years, all residents of northern and central Greece and 50% of the sample was divorced. All educational backgrounds were covered from high school graduates to PhD holders.

Table 2. Demographic Summary of Study Participants

Sample data			
Total Sample		n=30	100%
		n	%
Age		39-62	100%
Gender	Women	21	70%
	Men	9	30%
Residence	Northern Greece	19	63,3%
	Central Greece	11	36,6%
Marital status	Married	9	30%
	Divorced	15	50%
	Single parent	6	20%
Educational level	High school	14	40%
	Bachelor	12	46,6%
	PhD or MSc	4	13,3%

Limitations

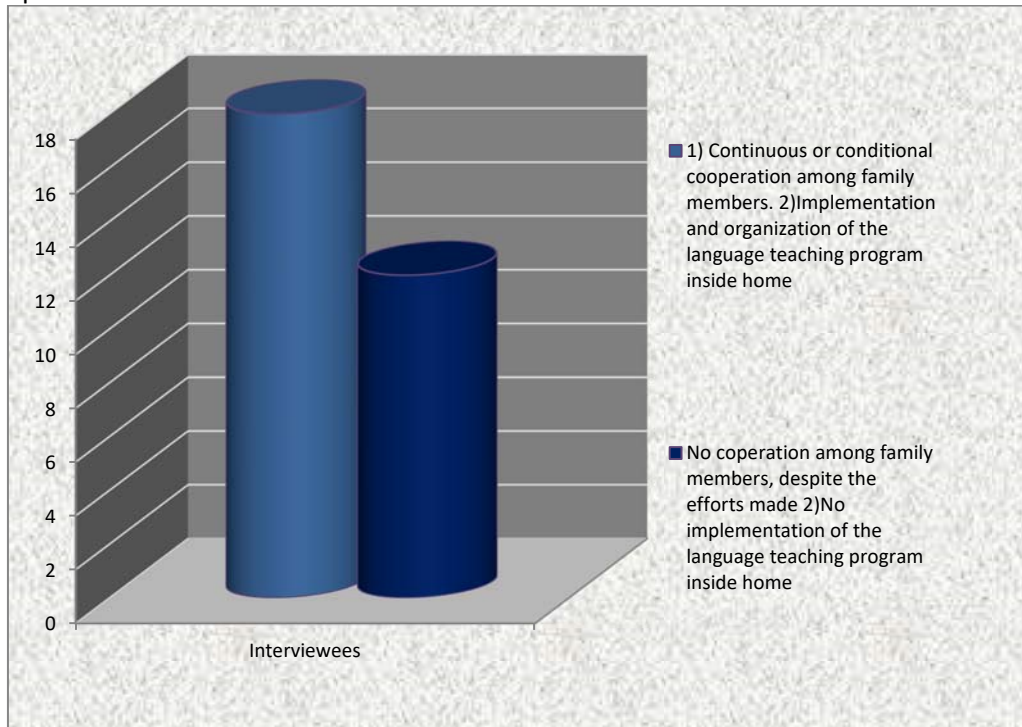
The research was carried out according to the original schedule without any serious problems. Covid-19 made the contact with the interviewees a little difficult, yet this was not insurmountable. Participants were informed about the research as well as about issues of anonymity and security of personal data. Semi-structured interviews were conducted on face to face meetings, according to participants’ availability. The data collection period started on the second semester of the academic year 2019-20 and ended the final days of the second semester of the academic year 2020-21.

The development of this research in the field of educational sciences involves a main handicap regarding the sample size. The initial virtues of this study were to put on the table the voice of parents with ASD adolescents who are not the object of constant studies in this field. The research was conducted in northern and central Greece and the results cannot be generalized to the total population concerned, since this is a qualitative approach with a relative percentage of participants. The small sample size does not permit generalizations to the entire population of parents with ASD adolescents for reliability reasons.

Findings

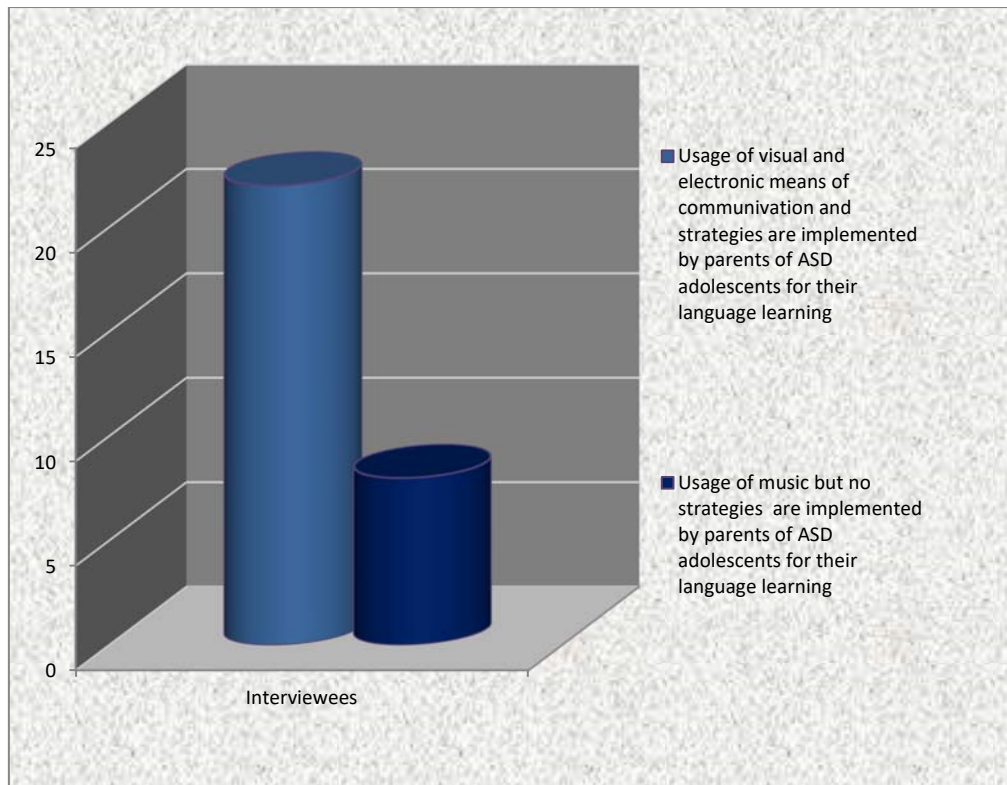
Family context factors that promote and prevent language learning in adolescents with ASD

The research data demonstrate that family environment is mostly presented as positive and collaborative inside home, trying constantly to promote language learning in their ASD adolescents. Mutual cooperation among family members regarding the communication with their ASD adolescent is continuous or sometimes conditional in most cases observed (60%, f=18), with the same percentages appearing in the implementation and organization of the language teaching program inside home. The percentage of 60% corresponds to 18 participants out of 30.



Graph 1. Cooperation among family members for the implementation of the language teaching program for their ASD adolescent inside home

The 30 interviewees were asked about the means of communication used with their ASD adolescent and the strategies they implement for their language learning. The vast majority of them apply certain strategies (as rewards and encouragement), visual and electronic means alone or complementary with written scripts (73,33%, f=22), and the rest do not apply strategies and use only music for their ASD adolescent language learning.



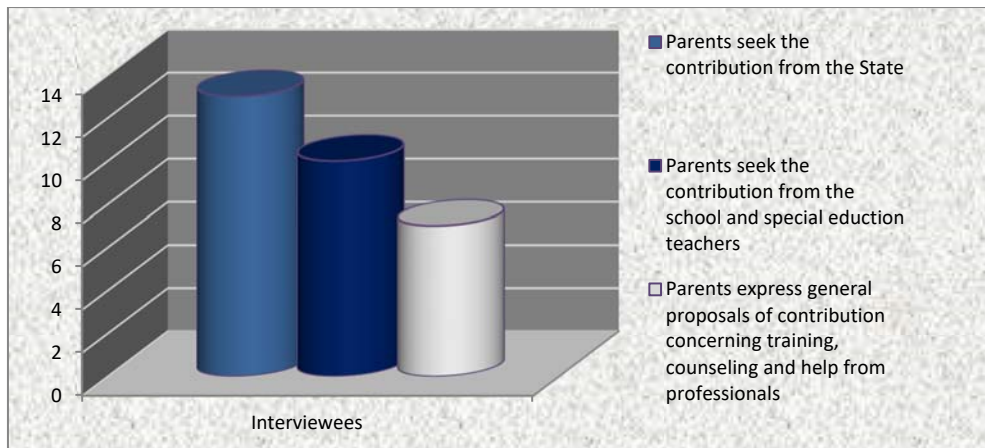
Graph 2. Means of communication and strategies used with their ASD adolescent for their language learning

The reaction of the participants to the possibility of following at home the pedagogical directions given from the school context is absolutely positive, with the 80%, $f=24$, to be in total agreement with this perspective and the rest arguing that this cannot happen, without specifying the exact reasons.

Detection of the pedagogical needs and demands emerged from parents of adolescents with ASD

The difficulties that parents-participants encounter in their adolescent's effort to respond to language learning reveal a clear separation among them according to the individual needs of each ASD adolescent. Thereby, parents whose children can speak and read adequately express mainly the deficiency of the misunderstanding of the real meaning (56,66%, $f=17$), while the rest, with ASD adolescents speechless or with limited vocabulary, argue that there is conditional or no communication at all (43,33%, $f=13$).

From the 30 interviewees, the vast majority (83,33%, $f=25$) recognize the crucial pedagogical assistance from special education teachers, in both guidance for their adolescent's language learning and their in-between collaboration. Yet, satisfaction levels are quite low since parents would appreciate more pedagogical help to facilitate their ASD adolescent's educational progress. From their own side the 80%, $f=24$, of parents, despite of their professional activities, apply educational techniques to facilitate their child's language learning, would require extra help though. They seek the contribution from the State (43,33%, $f=13$), the school and special education teachers (33,33%, $f=10$) and propose general suggestions concerning training, counseling and appropriate help from professionals (23,33%, $f=7$).

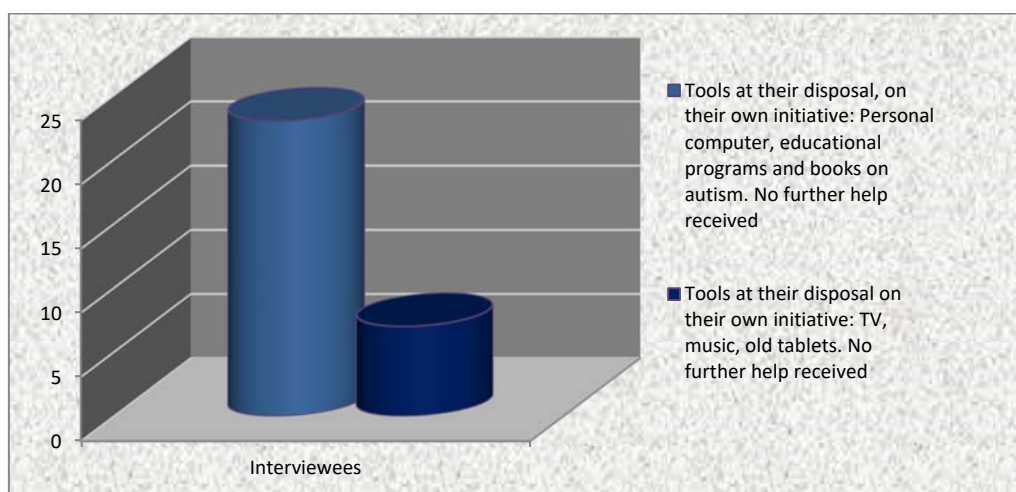


Graph 3. Pedagogical help that parents would appreciate to facilitate their ASD adolescent's educational progress

Value the role of the educational program within home

The educational objectives set by special education teachers for the in-home educational program, alongside with their in-between collaboration are achieved and unquestionable for the majority of the interviewees, since 76,66%, $f=23$, is confirmative. Additionally, work inside home is done through specific program and is completely or almost effective for the 73,33%, $f=22$, while the rest act spontaneously according to adolescent's needs and find the program ineffective or there is simply no program followed.

However, to facilitate ASD adolescents' linguistic capacity a lot of modifications are required for the family's program, with the 56,66%, $f=17$, of the interviewees to reschedule their working hours to comply and the rest of them, 53,33%, $f=13$, to be urged to stop working or get one day off from their work, during each week. Further, regarding the available tools parents have to promote the educational program inside home, almost all of them use their personal computer alone or combined with other tools they have gathered on their own initiative. In this case, their unanimous statement is that the State or the school context never provided them with any educational tools, nor further assistance is ever received.



Graph 4. Tools that parents have at their disposal to promote the educational program within home and which they have received

Discussion and conclusions

Greece presents a quite interesting example of a country where, despite supportive legislation, the provision of special education still faces obvious obstacles to its full implementation. From the obtained data, the classification of ASD adolescents into severity levels, combined with the diverse heterogeneity in their symptoms' appearance, is statistically insignificant, in terms of their parents' perception and attitudes regarding their language teaching. In short, and taking into account the objectives set, several aspects are concluded.

In relation to the objective family context factors that promote or prevent language learning for ASD adolescents, it can be argued that family environment is characterized as positive and mainly collaborative in most cases observed. These findings are consistent with the latest research of Ntre et al. (2018) in Greece who attributes these results to the strong ties in the extended family that are still observed in Greek communities. Concerning language learning and following a language teaching program for adolescents with ASD, this is implemented by visual and electronic means of communication, written scripts and music (Kotsi & Fernández Robles, 2023). This finding is fully in line with Knight & Sartini (2015), who maintain that visual supports are the first of the two evidence-based practices with a variety of forms, while using them is one of the most recommended practices in language teaching to students with ASD. The largest proportion of parents refer to considerable difficulties yet strive to apply an everyday language learning program inside home by implementing educational techniques, using learning strategies and endeavor hard to follow the pedagogical directions provided from the school context.

According to the objective detect the pedagogical needs and demands of parents of adolescents with ASD, it is admitted by the majority of the participants that collaboration at home between them and the special education teachers exists, yet satisfaction levels are quite low. Parents try to achieve the educational objectives set by special education teachers, but this is not always fulfilled (Kotsi, 2022). More often they try to apply a daily program in language learning with rewards, otherwise work inside home is progressed spontaneously according to adolescents' needs. Even when parents' cooperation helps their ASD adolescents show language improvement, there are serious exemptions. In this way, effectiveness of the implied educational programs at home is questioned and doubted. Parents seek for more collaboration and extra help from the school context, from special education teachers and from the State in general means. In accordance to the literature review in Greece of Kossyvakı (2021) it is apparent that legislation, policy and research have dealt with the parent-teacher collaboration to a certain extent. Syriopoulou-Delli et al. (2016) found that 100% of the parents and 96% of the teachers in their research sample consider the significant importance of parent-teacher collaboration. Additionally, the findings are fully in line with the research of Mavropalias et al. (2019), where parents do not seem satisfied with their collaboration with teachers, arguing that the information received from teachers on how to support their children on their education or guidance is not enough. As Veroni (2019) claims professionals need to respect parents' beliefs and provide appropriate information on the strategies to support ASD children and their families.

Regarding the objective evaluate the role of the educational program within home, the conclusion achieved is that parents mostly react positively and value its' role within home. Yet, according to the participants-parents, diversification and modification to the family program, in order to facilitate the adolescent's language abilities, is an essential factor. This includes shaping the working hours in such a way as to enable the engagement with the ASD adolescent and improve his linguistic skills. Whenever due to family reasons this cannot be achieved, then a day off during week or even quitting of job occurs, leading inevitably to financial burden. Findings are in complete consistency with Ntre et al. (2018), describing that 36,4% of families had a member who had to quit their job, in order to care for the child and that parents with a child with ASD were affected in their employment decisions by not taking

a specific job or greatly changing their current job or work extra hours, due to their availability to the proposed work hour-schedule. Ntre et al. (2018) claim that having a child with ASD is associated with a reduction in family income, with some parents obliged to modificate their professional career, in order to be able to cover the high cost of their child's special education. In addition, participants claim that the available tools at their disposal, to promote the educational program within home are depending exclusively on their own initiative: such as the usage of computers, tablets, educational programs and books about ASD, etc. No further assistance is offered, leading to comply with Papadopoulos's research (2021), where participants expressed financial strain arising from the overall cost of care for their ASD children, for both current and future treatment expenses.

Concluding, in modern Greece parents of ASD adolescents are facing the lack of the necessary technical infrastructure, absence of suitable resources and no funding. These effects hinder the positive development and psychosocial well-being of people with disabilities and cause long-term disadvantages (Thomaidis et al., 2020). Papadopoulos (2021) claims that the lack of access to equal opportunities in education may occur as such services offered by the State are minimal and do not best cover the holistic needs of adolescents and their families. Some attempts have been made in recent years for the overall improvement of the Greek education system, with the aim of including children with disabilities, but progress remains slow compared to the average progress achieved in the European Union (Papadopoulos, 2021).

Limitations and Future Lines

The initial virtues of this research were to put on the table the voice of parents with ASD adolescents who do not present the project of constant studies in this field. Access is limited though to northern and central Greece and the results cannot be generalized to the total population concerned or provide an overall scope of responses, beyond the study parameters.

Further, the research was conducted in Greece during an austerity period with financial cuts and reduced state financial support that affected education provision, particularly for families with ASD adolescents, whose educational needs are not met adequately. Other countries with similar socio-political structures may not, comparatively, undergo austerity in the same way, regarding seamless educational provision to all equally.

A future line of research should be focused on extrapolating the findings of the present study to other countries around the world, through the systematic approach of the parents of adolescents with ASD. Additionally, it would be very interesting to link language learning research between both adolescents with ASD in secondary education and children with ASD in primary education.

The final statement of the research is the central role that parents could perform in improving the language skills of their ASD adolescents. Placing them at the center of future research and transform them into accompanying assistants in the educational process, should be explored further.

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