

The Approach of the Albanian Reality to Autism Spectrum Disorder

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder associated with persistent deficits in social communication and social interaction across multiple contexts and restricted, repetitive patterns of behaviour, interests, or activities. The ways in which autism, culture and the education system interact have not yet been explored sufficiently, even more so when it comes to Albania. Through literature reviews, interviews, and case studies we aim to further investigate how autism is assessed and treated within the Albanian school system and how culture can affect the parent-teacher-child triangle. We also investigate the implementation of laws and policies regarding inclusive education, and its benefits to autistic individuals, specifically in the development of social skills that further help them to integrate into society. We also try to figure out the difficulties autistic individuals face within the school system and in their day-to-day life in Albania, as well as how Autism Spectrum Disorder affects the families of these individuals. This qualitative study found that the reality in Albania is not supportive enough towards autistic individuals. With further research into the field, we might be able to back this statement up with empirical data as well as figure out how this condition can be improved.

Keywords: *autism spectrum disorder, special education, cultural influence, inclusivity*

1. Introduction

Living in a society where prejudice is something that almost everyone holds within themselves, makes people of special target groups more aware of how others approach them. This is because, very often, it affects their quality of life and their psychological state. Autistic individuals for example, can be categorized

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as a vulnerable group that can be affected in considerable levels by the way the others approach them, including here not only the general public, but also the systems, laws, institutions, schools, etc., that are in place.

Autistic is the term referring people diagnosed with Autism Spectrum Disorder, which is defined by American Psychological Association as any one of a group of disorders with an onset typically occurring during the preschool years and characterized by varying but often marked difficulties in communication and social interaction. Autism Spectrum Disorder was formerly said to include such disorders as the prototype autism, Asperger's disorder, childhood disintegrative disorder, and Rett syndrome; it was synonymous with pervasive developmental disorder but more commonly used, given its reflection of symptom overlap among the disorders. It is now the official term used in DSM-5, where it encompasses and subsumes these disorders: Autism, Asperger's disorder, and childhood disintegrative disorder are no longer considered distinct diagnoses, and medical or genetic disorders that may be associated with Autism Spectrum Disorder, such as Rett's syndrome, are identified only as specifiers of the disorder. (Vandenbos)

This disorder caught our attention and inspired us to conduct this study as it is a very delicate and important matter of discussion. Another factor in deciding our study subject were the rising rates of Autism Spectrum Disorder diagnosis. Autism Spectrum Disorder has firstly been tracked by researchers in 2000 and had a prevalence of 1 in 150 children in United States, while in 2016 the prevalence was 1 in 54 children and the in 2017 was 1 in 44 children. (Wright, 2017)

With the growing number of autistic individuals, we thought it would be worthwhile to conduct a study which would focus on this category, to provide information so that we can come to their aid as much as possible. We added the frameworks of the Albanian reality to our study, to make the field of study more specific and tangible. Given the history, this disorder is considered new in Albania, so we find it more valuable to focus research on this country. This would provide more scientific information on this topic which is almost lacking for Albania.

In this study we aim to reach results regarding the way the Albanian reality approaches autistic individuals. When we say the Albanian reality, we are talking about the legal aspect, the institutional aspect and the human aspect and the way these work towards autistic individuals. We have tried to achieve this through a qualitative study method based on literature review and analysis of interviews conducted with competent people who can confidently talk about this field.

What is worth noting is the need that these individuals have for support and inclusion. They should be involved in life activities just like everyone else, but conditions should be created for them to cope with these activities on their own terms. This would help them to coexist better with their disorder and take steps towards development and improvement.

Description of chapters

Chapter I: This chapter provides a brief introduction to the topic to present its purpose, importance and perspectives.

Chapter II: The second chapter includes a review of the literature, in which various sources are reviewed to provide an explanatory framework regarding autism, Albanian law in support of it, and gender differences in treatment.

Chapter III: The third chapter explains step by step the study methodology, including the hypothesis, the research question, the objectives, the purpose, the relevance, the dependent and independent variables, the instruments used, the sample, and the restrictions.

Chapter IV: In this chapter the analysis of the data is done and in the case of our qualitative study it is organized in the form of a summary of the interviews and the main data provided by them that will help us to examine the hypothesis of the study.

Chapter V: In the last chapter, the conclusions of the study are given, considering the results obtained and verified hypothesis.

2. Literature review

Cultural influences on Autism Spectrum Disorder

As it stands today, the diagnosis of Autism Spectrum Disorder⁵ is one that not only affects the individual who receives it, but one that affects them along with their families, communities that they live in, the ways in which they interact with the healthcare system and the school system as a whole. Research on the impact of cultural beliefs specific to autism is very limited, although studies focusing on other developmental disorders suggest that it is influential. (Herbert & Koulouglioti, 2010).

Even though there is recent evidence that suggests that autism symptomatology is culturally influenced (Norbury & Sparks, 2013; Zaroff& Uhm, 2012), as it stands today, the ways in which culture specifically impacts people with ASD and their families is insufficiently researched. Cultural context has been shown to influence the expression, recognition, interpretation, and reporting of autism symptoms. (Leeuw et al., 2020) Despite the lack of research, a number of studies have also pointed out the importance of further researching the ways in which the families respective culture influences the way they view autism, how they understand and interpret autism symptoms and finally the treatment options they choose to move forward with, if at all.

⁵ From here on after, Autism Spectrum Disorder and ASD will be used interchangeably

On the other hand, the same factors must be pointed out when it comes to the way culture influences the professionals' point of view and how they choose to utilize different diagnostic instruments for ASD and offer treatment options. It is important to focus on both macrolevel cultural factors—factors at the dominant culture level that affect the people in that society and microlevel factors—factors at the family level that affect response to diagnosis or treatment choice. (Bernier et al., 2010) There is a consensus between practitioners that there exists a need to conduct further research on how autism may present in middle- and low-income countries, typically non-western ones.

The importance of the role gender plays in the perception of ASD

Parallel to the research that strives to explain the effect of how a culture overall affects the way autism is viewed, there is also an increasing number of research that points to the importance of addressing and explaining the specific role that the social construct of gender plays in the perception of autism symptom severity. (Geelhand et al., 2019) As pointed out by a few studies measuring cognitive differences in boys and girls conducted by the Journal of American Academy of Child & Adolescent Psychiatry there do seem to exist a few differences between them, specifically in the area of adaptive skills, problem-solving and problem externalization, overall cognitive ability and intellectual level. (Dworzinsky et al., 2012; Frazier et al., 2013)

Other studies have concluded that there are few to none gender differences when it comes to autism symptom severity and the areas where there do seem to be slight differences, it was mostly a matter of differences in IQ and age. (Rivet & Matson 2011) The most widely reported male–female ratio for autism prevalence is 4–5:1, lower in individuals with intellectual disability and higher at the high-functioning end. (Fombonne E., Quirke S., Hagen A. 2011) The overall nature of the studies who have taken such subjects into consideration is one of contradiction, leading to the relationship between gender differences and autism symptoms to remain unclear and complicated.

Parent – teacher-child triangle

The lack of studies on the topic of cultural influence and gender differences in autism, also seems to bleed into a lack of studies in the area of parent-teacher-child interaction and cooperation when the child is diagnosed with ASD, especially when it comes to families that are part of a cultural minority. There seem to be two main ways through which this triangle is maintained, one is through the co-development of teaching strategies and the other is through parental

training facilitated by special education teachers and the school system. These have not only shown positive results in the management of autism symptoms of the child, but also perceived as very beneficial by the parent. (Kashinath Sh., Woods J., Goldstein H., 2006) As such, the utilization of such strategies and guidelines such as the 2nd Edition of Kids in the Syndrome Mix of ADHD, LD, ASD, Tourette's, Anxiety and More.

The main conclusion that is presented in studies around this topic comes down to the importance of sharing knowledge with parents, communities, and individuals. Something that would increase public awareness of available services and resources for culturally and linguistically diverse children with ASD and their families, and thus help them access usual sources of care. (Lin, Yu & Harwood, 2012) Parent-implemented PECS training showed that through such an intervention parents can effectively implement improvisation training and a clear relation between parent-implemented training and improvisation of mands by children with autism. (Chaabane et al., 2009)

As for minorities, parent-focused interventions do not seem to address their issues as effectively. Rather, it was shown that ASD education programs that address informational and cultural needs may better promote ASD adjustment among ethnic minority families. (Gordillo M., Chu A., Long K., 2020) Another very important point to mention is the importance of providing documentation and resources for families in their native language. This would help practitioner understand and respect cultural difference, and thus contribute to the delivery of family-centered service. (Barrio et al., 2018) Studies clearly point to the importance of combining research-based interventions with the understanding and respect needed to provide useful resources to parents and families that are a part of a cultural minority. Doing so will ensure the well-management and functionality of the parent-teacher-child triangle, resulting in a better education experience for the child diagnosed with ASD.

There are a lot of factors to be considered while examining the significance of education for children with ASD; this can vary as of: class formation, teacher's attitude, assistant teacher ease of access, parent-school-child triangle (Brooker, 2010), the role of school psychologist, inclusive or exclusive education style, infrastructure and physical environment, practices challenges&IEP. "Due to legal and therapeutic reasons, children with autism spectrum disorders (ASD) are often educated in general education settings. As such, it is important to understand the variables that might affect a student's placement in inclusive education settings, simultaneously considering student variables (e.g., disability label) and teacher variables (e.g., knowledge of autism)." (Matthew J. Segalla, 2014) Teaching children with ASD can be quite challenging for teaching staff. ASD can take unique forms in different individuals therefore, not every child with

ASD will necessitate additional staffing and specialist placement. Nevertheless, all children can benefit from staff that has professional knowledge of ASD, with diverse teaching style; and from an adjusted education environment. “First, they need to help the child in managing the classroom and school environment. This may involve reorganizing the furniture; labelling areas and equipment; providing a dedicated work area; or teaching the children strategies with which to interpret and respond to demands as they arise” In example using Social Stories and visual timetables. (Gray 1994; Smith 2001) & (Mesibov& Howley 2003)

Autism Spectrum Disorder in Albania

The law for inclusive education in Albania

Albanian law that discusses special education for children with disabilities is included in the 11th section of law number 69 published in 2012 concerning the pre-university education system, containing three articles in total, namely Article 63, Article 64 and Article 65. Along with the three articles included under the aforementioned section, there is also Article 19 under section number 2 “EDUCATIONAL INSTITUTIONS AND FORMS OF EDUCATION” of the same law. Under Albanian law, services for students with special needs are ensured by the state (Article 19, Law nr.69,2012). The ways in which these services will be delivered and the criteria needed to be able to receive such services is decided by The Council of Ministers, as explained by Article 19 of Law number 69,2012. Section 11 titled “EDUCATION FOR CHILDREN WITH DISABILITIES”, as stated above, contains three articles, each containing three, six and four main points respectively. The first one, Article 63, states the three main principles around education for children with disabilities, SD being a diagnosis that puts a child in that category. It explains that the goal of special education for these children should be to help them achieve their full physical and mental potential, while also improving their quality of life. Furthermore, it states that the inclusion of children with disabilities in ordinary schools is of primary importance and also the guarantees the right to communicate through sign language and the usage of Braille writing. Article 64, titled “THE ATTENDING OF EDUCATIONAL INSTITUTIONS BY CHILDREN WITH DISABILITIES”, consists of six main points and describes the role of specialized institutions in the process of attending educational institutions by children with disabilities and also the role that the parents play in deciding whether or not their child will or will not attend such institutions. Article 65, titled “ORGANIZATION OF EDUCATION FOR CHILDREN WITH DISABILITIES”, consists of four main points. It describes the ways in which children with disabilities may follow the course of a certain subject, whether it be alongside other students via the

ordinary teaching plan, a teaching plan adjusted to their needs or one that is made specifically for them. The role of the parent in this entire process is also included, stating that the development of the personalized education program is done in collaboration with the child's parents. (Article 65, Law nr.69, 2012) Even though such law acknowledges the importance of special education services, the inclusion of the child's parents in the process of making decisions regarding their child's education and the role specialized institutions play in the education of children with disabilities, it still lacks important points regarding the support that should be offered for the needs of children with disabilities, while also excluding children who show signs of social maladaptation from receiving special services. Overall it is characterized as a legal document that offers limited information and guidelines as to how children with disabilities fit into the education system.

The Albanian education system in relation to ASD

A study conducted in the Albanian education system indicated a lot of tasks and issues regarding the quality and services offered in schools. "Related to the barriers of children with learning difficulties in compulsory education. Autistic children, similarly, to all children with learning difficulties, face and are hindered by a considerable number of barriers. These barriers can be structural, pedagogical, conceptual, professional, financial, and behavioral. The group of autistic children faces specific barriers at a different level, when compared to other children with learning difficulties." (Gjedia, 2015) Correspondingly in parents' voices these obstacles in the Albanian education environment are regarded as fundamental in their children's optimal development. "In terms of what parents feel is most needed for the provision of an appropriate education for their children, almost all studies examining this question specifically mention the need for specialized teacher training and knowledge of autism, effective collaboration and communication, staff being able to manage the child's behavior, the child's progress in terms of social skills, and the need for structure." (Foy, 2012) An additional question that originated during the conduction of the research was: "If provided mainstream education or special school education which would be the best way to support ASD children optimal development?" "National Autistic Society Northern Ireland (2012) survey identified that more than one in four children do not feel happy at school with almost one-third of parents indicating that the education their child gets is inadequate to meet their needs." (Marshall, 2015) Additionally, less than half of the parents repeatedly have to take their child out of school because of the difficulties that staff has to go through to handle aggressive behaviors. This situation in an Albanian context can get more problematic due to parents' approach. Mainstream schools and

neurodiversity classrooms can be challenging for all components, then again: “The benefits of mainstream inclusion for children with ASD include displaying more social behavior, having more advanced education goals” (Elder et al. 2010) and increased social skills (Reiter and Vitani 2007). Certainly, benefits of general/inclusive education setting can vary from improved social skills due to modeling of typical behaviors, lower stigmatization and improved self-concept, advanced academic expectations. (Mesibov & Shea, 1996) Although teachers, psychosocial experts and REA representatives recommend that for the Albanian context and conditions it would be a better choice not to include all children in regular schools. “Some extreme cases that need a caregiver, besides an assistant teacher, recommend being put in special education institutions until they make progress. They mainly mention cases of children that are not able to care for their hygiene (e.g., they urinate in class or take their clothes off) or others that have aggressive behaviour towards other children or teachers.” (Duci, Ndrio, Dragoti, (Nasufi), & Ismaili, 2016)

Literature indicates the importance of mainstream inclusive education, nonetheless specifies the importance of IEP (Gartin, 2005) & assistant teacher and staff. IEP functionality interconnects with teacher’s behavior and child engagement & response. Studies have pointed out that the success of IEP is equally dependent on a child’s reaction to the setting and its quality. (Ruble, 2013) Referring back to the Albanian setting, IEP and assistant teacher & staff seem challenging. “In most cases, their individual plans do not meet the real needs of students with autism. Individual Education Plans, in most cases are written by the teacher and are not built by a specialized team that is capable of such task.”(Gjedia, 2015) Another prominent element in in the revised literature is the importance of teachers’ attitude towards autistic children. “Positive teacher attitudes are an important predictor of the successful education of children with disabilities, including those with autism spectrum disorders.” (Rodríguez, 2012)

Parents’ Perspective on ASD

There’s a lack of literature on the parents’ perspective in the Albanian setting therefore we have referred to cross cultural studies to thoroughly link to the perspective conveyed by the interviews conducted. Parent’s perspective is important, regarding the amount of time they spend with their children. Parents can express moreover what the children may not be able to express analogically. Their perspective is not only their experience but also the children’s experience. In a survey conducted in 2012 by Elizabeth M. Starr and Janis B. Foy: “Parents stated that what is needed are “fully trained experts of any profession, so I need not be the only expert (really, I do all of the programming). These quotations also highlight the commonly expressed frustration related to the parents ‘perceived

need to educate their child's teacher each year." Some of the most common needs that parents mention in surveys are increased educational assistant time, the incorporation of technology, increased assistant time in education, social skills training, and sensory integration. Various literatures point toward parents commonly wanting their autistic children to reach their full potential in life.

Another valuable component of education for autistic children is the psychologist. The psychologist assists not only the children but also serves as care coordinator for the child- school-parent triangle. School psychologists are positioned to facilitate care coordination because they possess the required training. In domains such as: child development and developmental disabilities, constructing data-based resolution and offering consultation, professional academic and mental health mediations, psychological assessment, affiliating with families and other disciplines and structures. "The concept of care coordination assumes a central role within the National Association of School Psychologists'(2010) Model for Comprehensive and Integrated School Psychological Services" (NASP Practice Model) (Shahidullah, 2020)

3. Methodology

3.1. Study purpose and research question

The purpose of this study is to analyze the reality and the culture that individuals diagnosed with Autism Spectrum Disorder face in Albania. By gathering data on the day-to-day activities of autistic individuals as well as their interactions with others, we may be able to understand what the general approach to autistic people in the Albanian society is, whether it be cultural or legislative.

Objectives:

- In this study we aim to reach these main objectives:
- Understand how the law in Albania affects the life of autistic individuals
- Understand how the law for these individuals is implemented, especially in schools, as it is one of the main institutions in which autistic individuals are part of and affected by.
- Understand more about the school system and its' efficiency for these individuals
- Understand the difficulties that these individuals face in Albanian reality
- Understand the approach of other people toward these individuals
- Understand how these individuals are seen by the society and cultural aspects

Research question: What is the reality of the approach towards individuals diagnosed with Autism Spectrum Disorder in Albania?

Hypothesis:

In this study we aim to confirm these hypotheses:

Hypothesis 1: The reality in Albania is not supportive enough for individuals diagnosed with Autism spectrum disorder.

Hypothesis 0: The reality in Albania is quite supportive for individuals diagnosed with Autism spectrum disorder.

Variables:

In this study we have two variables from which one is dependent and one independent. Respectively the dependent variable of this study is the approach of the Albanian reality and the independent variable are the autistic individuals.

Study analysis:

In this study the main analysis is based on a methodology of a qualitative study model. Qualitative research is the process of collecting, analyzing, and interpreting non-numerical data, such as language. Qualitative research can be used to understand how an individual subjectively perceives and gives meaning to their social reality. (McLeod, 2019) To collect data about our study we chose to interview some individuals that are in contact with this reality on a daily basis and are competent to give opinions and evidence about the situation of individuals diagnosed with Autism Spectrum Disorder in Albania. We believe that this model is the most appropriate one for our study thesis as it allows for gathering more extensive information as well as specific details. We have used the semi-structured type of the interview, with pre-prepared questions as well as additional questions that were asked based on the course of the interview.

Why is this study important?

This study has considerable importance especially in Albania. By gathering information on the ways in which autistic individuals interact with the social environment, in their day-to-day life as well as within establishments such as schools, we may be able to highlight the difficulties these individuals are faced with, and where these difficulties may stem from. By talking to professionals, we can figure out what needs to be done to get the best outcome for autistic individuals. By compiling both, the law for education and firsthand experiences of the people who are constantly in contact with autistic individuals, we will be

able to check how well these laws are implemented. This study can also help in opening a path to further research, both qualitative and quantitative, in order to get a full picture on the reality that autistic people face in Albania. With further research that can provide empirical data for the field of studying ASD, we may be able to bring forth positive change in the lives of autistic people, whether it be by bringing awareness, reducing stigma or even influencing the legislation.

Participants

As mentioned before, in this study we tried to seek information from individuals who have significant contact with autistic individuals, including here psychologists, parents of autistic children diagnosed, and special needs learning support assistants. Respectively we have interviewed two parents of two autistic boys, one psychologist for children and adolescents and two special needs learning support assistants. For parents, as it is clear that they spent most of the time of their day taking care of their children diagnosed with Autism Spectrum Disorder, they have a lot of information about how their children are seen by others, how the law supports them, how they are involved in school lessons and how efficient is this process for them and all other objectives that answer our research question. About the special needs learning support assistants, their everyday work is to assist these individuals in schools, so they know what the difficulties they face during the learning process are. The psychologist also works with autistic individuals, and has a wide experience with them, therefore she was able to share more formal and organized information about all our questions.

Methodology

The process of conducting this study has passed through some phases. We initially decided on the individuals we should collect information from and realized that there are three key figures that have a significant role in the life of autistic individuals of all ages: parents of these individuals, psychologists and special needs learning support assistants. We proceeded to find our contacts and reached out to them for an interview. As mentioned above, we found two parents, a psychologist and two special needs learning support assistants that accepted to share with us their information anonymously except for the psychologist and one of the special needs learning support assistants. They agreed to share the evidence they have witnessed with sincerity and objectivity based on facts and situations. We prepared the questions for each group that would be interviewed, resulting in a different set of questions for parents, a different set of questions for the psychologist and a different set of questions for the special needs learning support assistants. We set the dates for the interviews,

which were held on different days and from different people. Every interview was recorded as evidence for this study. After completing the interviews, we made the transcriptions and organized the data collected from the answers of the people who were interviewed. We proceeded to prepare a detailed analysis of the data so we could reach the conclusions of this study. In the end of the process, we controlled the hypothesis and understood which one was proved.

Instruments

Instruments used for this study consist of the interviews we had prepared to gather as much information as needed to collect the data we wanted. The interviews were semi-structured and created by us, so not based on a standardized inventory or questionnaire. The interview of the psychologist as well as the interviews of the special needs learning support assistants consisted on a different number or questions based on the natural flow of the conversation and information they were willing to share. The interview of the parents consisted of a different number of questions from each other because of the age of the children diagnosed with Autism Spectrum Disorder, so we decided to focus the attention of our interview in different aspects for these two individuals. The questions of the interviews on each group were mostly open-ended questions, based on their experiences with autistic individuals, their evidence about the life of these individuals, the way they think and approach with these individuals, their understanding of others culture and approach to autistic individuals, etc. We have adjusted by adding new questions and not using some that we have pre-prepared on the process of interviewing because of the dynamics of the interviews and the information we aimed to collect the most.

Restrictions

This study, because of its nature, has some restrictions which we are going to list below. As it is a qualitative study, there is a small number of interviews to take into consideration and this stops us from being able to generalize on our conclusions. We give conclusions based on the detailed information we collected by our interviews, but we cannot say that these interviews express all the Albanian reality about autistic individuals. Another restriction for this study is also the instrument used, that is not standardized but self-created. However, the questions are adapted to the purpose of the study, and we tried to choose the best ones that could help us collect the information we needed. Even with these restrictions we have respected all ethical rules and a strictly objective process, from which we could build our data base and reach reliable conclusions which others can take into consideration for further quantitative studies.

4. Case overview

First interview

The first interview was conducted with S. A., special needs learning support assistant. She expressed that inclusive education is crucial when it comes to these Children. She reported that the biggest challenge when it comes to special needs education is the introduction process, especially when it comes to children on the autism spectrum. She linked establishing a good relationship with the child to a form of testing, both on the teacher's end and on the child's end. The child through their behaviors creates a block, which makes it very hard for the teacher to connect to them. However, she expressed that if these children were allowed to be themselves it would create a better atmosphere in the class. It is also worth noting that this would allow both parties to experience very positive emotions. For Ms. A. the main issue with special needs education was related to the adults, who allow their own opinions and mentality to affect the quality of education. Both, the teacher, and the special needs learning support assistant, need to focus on inclusivity to help create harmony between all the children in the class, Ms. A. stated. She regurgitated that it is very important to allow autistic children to be open and try to interact with others, as well as the fact that most issues arise from the adults in these settings. She put emphasis on the fact that each behavior that autistic children exhibit has the function of trying to communicate something specific to the teacher and it is up to the teacher to decode it. To conclude, Ms. A. distinguished between successful and unsuccessful cases when it comes to autistic children. Success cases for her were the ones in which nonverbal children become able to speak and express themselves.

Second interview

The second interviewee was also a special needs learning support assistant who shared her experiences with us. She believed that integrating autistic children in inclusive classrooms helps them interact better with others. She stated that during her experience she has mainly worked with the other children in the classroom. She considered this work very important as by explaining and familiarizing other children with the concept of autism spectrum disorder she had been able to help them cooperate with the autistic children in the class. She had also observed that other children who interact with autistic children had become more empathic and more willing to cooperate, as well as more accepting to the idea that everyone is unique. She recalled her most successful moment

of her career as a case in which the child was unable to stay in class for the full length of the lesson, however by the end of the year, the same child actively participated in a celebration the class held.

Third interview

The third interviewee was the parent of an autistic child who shared her struggles with us. She stated that the hardest part of this journey was accepting that she had an autistic child. As she was not informed on autism spectrum disorder, when the child was very young, she believed that he would speak very soon, and it was no cause of concern. She claimed that accepting that her son needed help was the first step in helping him. Afterwards, her son was assessed by a multidisciplinary team and was diagnosed with autism spectrum disorder, and they started the process of taking him to therapy. She states that though it is a hard process, both emotionally and financially, her son is now better. In the end she expressed again how important it is to accept autistic children, be it acceptance from the parents or other children in inclusive classrooms.

Fourth interview

The fourth person to be interviewed was Ms. K. Sh. who works as a psychologist for children and adolescents. She stated that the policies to create inclusive classrooms have been revolutionary in autism awareness as well as in integrating autistic children in society. However, she noted that due to the high number of students in a class, managing them becomes difficult, therefore it is necessary to have a special needs learning support assistant that caters to only one or two autistic children. She then talked about the difficulties of implementing inclusive education in Albania. Ms. Sh. said that the infrastructure was the first difficulty, bringing as an example the classroom décor that can cause sensory problems for autistic children who deal with hypersensitivity. The second point she brought up was getting to know the child and recognizing specific behaviors they exhibit that might need intervention, something that teachers often have troubles with. For this exact reason, Ms. Sh. believed that the best help can be offered through a team consisting of the teacher, special needs learning support assistant, psychologist, social worker. Another topic that came up was the curriculum, which needs to be adapted to autistic children through the usage of individual education plans and specific classes that offer sources for children with special needs. The latter is very limited as these classes are not available in every school. When asked about the most effective method of helping these children, Ms. Sh. said that it goes on a case-by-case basis, but mostly focuses on teaching social skills as well as integration into social activities organized by the class and interaction

with peers. When asked about the most important thing to keep in mind in this field of work, she noted three things: being sensitive to the child's needs and emotions, listening to the child, group collaboration. When asked about her most successful case, Ms. Sh. brought into attention the fact that improvement in autistic children is slow, extended in time and with very small steps, but she mentioned a case where a child had managed to be integrated into groups. When asked about the importance of inclusive education, she mentioned that not all autistic children should be part of inclusive classrooms because some might require more specialized treatment and only after these treatments become part of inclusive classrooms, however it is important for everyone to recognize and accept people who are different from our own self.

Fifth interview

The fifth interviewee is the mother of a 20-year-old autistic man. She explains that originally, her son was being helped by professional and offered ABA therapy, up until he was 14 at the Regional Autism Centre. Since he left, he has been taking medication, which the mother states do not help him. She also regretted not having given him a sedative medication she was suggested when he was a child to calm his anger. She recalled a certain incident in which her son had become violent, hurting both her and her husband. They brought him to a hospital and isolated him in order to have him calm down as they were unable to restrain him. She claimed to often feel hopeless as the violent outbursts of her older son have become a threat to their youngest son. When asked about her opinion on the current treatments offered in Albania, she again recalled a specific incident. When her son was following treatment at the above-mentioned facility, he had gone to the gym where he had been hit by the professionals or the therapists supposed to help him. When she had gotten in contact with the higher ups, she was told that there was nothing they could do and had put the blame on her son's behavior. Though the situation was later resolved, it led her to believe that there is no facility that can help her son. She stated that to improve the quality of help offered to autistic children, the main thing that needs to change is for people, specifically professionals, to be more open-hearted and compassionate towards these children. She described life with ASD in the family as an ongoing struggle that affects every single member of the family. She also opened about financial struggles that come with having to pay for therapy and medication as well as worsening mental health due to the situation she was currently in. She concluded the interview by stating that the most important thing when it comes to dealing with ASD in the family is accepting that you have an autistic child and helping them follow are the necessary therapies.

5. Discussion

As stated previously, the purpose of this study is to reveal the reality and the culture that individuals diagnosed with Autism Spectrum Disorder, face in Albania. The research question which this study aims to give an answer to is: “How does the reality in Albania approach individuals diagnosed with Autism spectrum disorder?”.

From the interviews conducted, we aimed to gather information on the point of view of both professionals and parents of autistic individuals to paint a fuller picture of the realities that autistic individual face. We also reviewed the laws in place and the support they offer for autistic individuals.

Hypothesis 1: The reality in Albania is not supportive enough for individuals diagnosed with Autism Spectrum Disorder.

As it stands, the law does not have a specific section that caters to autistic individuals’ needs. It only refers to what is offered to special needs students, within all categories, to facilitate their learning processes.

In article 63, section XI of the “Law on Pre-University Education” it is clearly stated that inclusive education is the end goal of special needs education in Albania. This aligns with the findings of the interviews conducted with special needs learning support assistants and a psychologist, in specific interviews 1,2 and 4. Throughout all three of these interviews, it is noted that, for autistic children, taking part in inclusive classrooms is crucial to their development. This is because it creates the tools and develops the skills necessary to be integrated into society as they grow up. The second interview emphasized the positive impact inclusive education has on other children as well, as it allows them to become more accepting and empathic. These findings are further backed up by studies reviewed previously such as Mesibov& Shea (1996), which speak to the benefits inclusive education can offer.

In the meantime, though inclusive education is the end goal for Albanian education, there are a lot of difficulties that come with implementing it into the existing education system. These difficulties were brought to our attention by the interviewees in the first, second and fourth interview as well. Specifically, in the fourth interview it was noted that the infrastructure is a big problem as it can cause reactivity in autistic children. Another issue is the curriculum, which is not fully adapted to autistic children. The studies reviewed also note the importance of Individual Learning Plans, plans that according to Gjedja (2005), do not meet the needs of the students as they are not compiled by the professionals necessary in this process.

It was pointed out, in interviews and in studies, that the approach teachers and professionals have towards autistic individuals may pose an issue as well. More

specifically, on our first interview, it was stated that adults often allow their own mentality and opinions to affect the quality of education offered. From the fourth interview we learn that teacher may have difficulties recognizing certain behaviors in autistic children, and thus are not able to offer the help needed. As Rodriguez (2012) stated that positive teacher attitudes are crucial predictors of the success of special needs education, it is clear to see that Albanian special needs education lacks in this regard.

All three interviewees who are involved in the education process as professionals (interview 1,2,4) defined success for autistic children in similar ways. For them, a case would be considered successful the moment that autistic children are able to interact, integrate, and cooperate with other children in groups. From the interview conducted with a psychologist we learned that though this progress is achievable, it is slow and in very small steps. This approach to success seems to also be in line with what one of the parents we interviewed said, in our third interview.

We also examined what autistic individuals face outside of a classroom setting. For this, the interviews conducted with children of autistic individuals come to our aid.

In both interviews we found one common problem; the parents' unwillingness to accept that their child has autism and will need special help. In the third interview we conducted, the mother of an autistic child states that she herself had trouble with this notion when the child was very young. This becomes an issue as in the "Law on Pre-University Education", section XI, article 64, it is stated that the parent can decide which educational institution their child will be part of, as well as deciding to pull their child from school at any moment. If the parent is unwilling to accept that their child needs special help and force them to go through an educational path that does not cater their needs, it can hinder the child's progress. As there is a lack of literature regarding parent's perceptions, these conclusions are only pulled by our own research. However, there is evidence that the implement of parent training can improve the conditions of an autistic child (Chaabane et al., 2009).

From the last interview conducted we also learned of the discrimination autistic individuals face in their everyday life. One instance was retold by the mother of an autistic man where he was physically abused in an establishment that was supposed to help him. This incident was later blamed on her son. This aligns with that the first interviewee stated when it came to the fact that professionals allow their own opinions and perceptions to affect the way they offer help. This negative biases towards autistic individual may be what Bernier et al. (2010) and Leeuw et al. (2020) were referring to when they spoke about cultural influence in the expression, perception and help offered to autistic individuals. Furthermore, it may be one of the barriers that autistic individuals face, as Gjedja (2005) stated.

Both parents of autistic children interviewed spoke of the financial difficulties they were faced with once their child was diagnosed. The third interviewee only mentioned that the treatment for her child was a financially taxing process. Meanwhile the fifth interview went more in detail on this regard. While she stated that she her son was given help up until the age of 14 at the Regional Autism Centre, she also talked about the numerous medication that he had to be on. Thus, continuous therapy, medication, emergency situations and further intervention were all very costly processes that worsened their financial state. Furthermore, as autism does not only affect the autistic individual, but also their family, she mentioned that she herself had gone to therapy. Thus, more costs were added as mental health help is also necessary for the other members of the family.

Conclusions and recommendations

Will all the information we gathered from reviewing the existing literature, comparison to previous studies conducted in Albania, as well as the firsthand experiences of special needs learning support assistants, a psychologist, and parents of autistic children, we conclude that our hypothesis is proven as correct. Thus, the reality in Albania is not supportive enough for individuals diagnosed with Autism Spectrum Disorder. We also reached our goals of analyzing how the law, education system and culture affect autistic people in Albania.

However, as the study we conducted is of a qualitative nature, we cannot generalize our conclusions as pertaining to the whole Albanian reality. We may say that these conclusions reveal a part of how the reality in Albania is for autistic individuals, based on the limited information we were able to gather through interviews. It is necessary for further quantitative studies to be conducted to generalize. This study still has weight in the field as it provides firsthand accounts of people affected by autism as well as people who support those affected. Furthermore, it can offer recommendations for future studies, such as studies on the perception of parents of autistic children on the special education system in Albania. Quantitative studies in the future can also shed light on the discrimination autistic individuals face in our society.

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