



RESEARCH ON AUTISM IN KOSOVO

DETAILED MEASUREMENT OF
GROUP NEEDS THROUGH PARENTS
OF CHILDREN WITH AUTISM

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CHILDREN WITH AUTISM**

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ABBREVIATIONS AND ACRONYMS

AAS	Analysis and Behavior Applications
ABA	Applied Behavior Analysis
ADI-R	Autism Diagnostic Interview - Revised
ADOS	Autism Diagnostic Observation Schedule
ANAK	National Association of Autism in Kosovo
CARS	Childhood Autism Rating Scale
CDC	Centers for Disease Control and Prevention
DSM	Diagnostic and Statistical Manual of Mental Disorders
GARS	Gilliam Autism Rating Scale
ICD	International Statistical Classification of Diseases and Related Health Problems
PECS	Picture Exchange Communication System
QKUK	University Clinical Center of Kosovo
SPSS	Statistical Package for the Social Sciences
VB	Verbal Behavior

EXECUTIVE SUMMARY

This research is an attempt to evaluate in detail the needs of children with autism in Kosovo and the existing services that are available, as well as the need for the health insurance scheme to cover autism services. In order to measure these needs, 42 structured interviews were conducted with parents of children with autism using a questionnaire.

The research participants resided in seven regions of Kosovo; residents from the region of Prishtina dominated, with 66.7% of the total, while the rest were from other regions. The research findings demonstrated the absence of multidisciplinary teams during the diagnostic process in Kosovo. Seventy-six percent of participants stated that there was no team present during the diagnosis of their child. Treatment in Kosovo is dominated by ABA and VB, with 64.3% of participants indicating that they were beneficiaries of these services, while others receive ABA services with PECS, ergotherapy, and logopaedics.

Among the interviewed participants, 38.1% stated that their incomes varied from 0 to 350 euros per month, and 33.3% declared incomes from 351-600 euros per month, while only 28.6% reported incomes over 601 euros per month. Monthly costs for an autistic child, according to the statements of participants in the research, averaged around 294 euros per month. Approximately 86% of participants stated that their families had difficulties covering expenses for their children with autism.



INTRODUCTION

Autism is a pervasive developmental disorder characterized by challenges in three basic areas of operation: difficulties with social interaction; difficulties with communication; and repetitive behavior and obsessive interest in specific things (American Psychiatric Association, 2000). Autism develops in the first three years of life, usually in infancy (Lord, Cook, Leventhal, & Amaral, 2000). In the first three years of life, social skill deficiencies are not so obvious, but they become more evident in subsequent years.

The prevalence of this disorder in Kosovo is not yet known. A review of global autism prevalence assessments in 2012 found that 62 out of 10,000 people worldwide suffered from autism (Elsabbagh, 2012). In 2014, the Centers for Disease Control and Prevention (CDC) published data on autism prevalence in the United States of America. This study found that 1 in 68 children in the United States had autism (1 in 42 boys and 1 in 189 girls).

The criteria for identifying and diagnosing autism are very specific. Specific treatment services have been developed as well, which are designed to stimulate the development of skills and potentials in persons with autism, as well as to increase their integration and independence.

However, the disadvantage of these services is that they are very costly, as Applied Behavior Analysis (ABA) principles require 1:1 therapy (one child – one therapist). Despite the high cost of this service in Kosovo, it must be covered by the family budget due to the lack of a health insurance scheme, as well as the lack of inclusion of this service in health insurance scheme proposals.



Autism is usually diagnosed by combining clinical observation and the child's history as described by the parents, applying criteria from the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Statistical Classification of Diseases and Related Health Problems (ICD). A common practice of psychologists in developed countries in the diagnosis of autism is the use of standardized tests to examine clinical development, including the Gilliam Autism Rating Scale (GARS) (Mick, 2005) and the Autism Diagnostic Interview (ADI-R) (Hendricks, et. al, 2013). Other assessments are made through discussions with parents using the GARS (Gilliam, 2006), behavior observations using the Autism Diagnostic Observation Schedule (ADOS) (Hendricks, et. al, 2013), and observing the patient's understanding and expression of language.

In Kosovo, according to information received from the Psychiatric Clinic for Children and Adolescents, there are no translated and adapted assessment instruments in the Albanian language, although autism diagnosis is done by GARS. However, despite the shortcomings in diagnostic services, clinical services are provided free of charge.

Several programs developed for direct work with children with autism have been shown scientifically to be effective. One of the most notable programs is Analysis and Behavior Application (AAS), which deals with developmental and behavioral deficiencies by manipulating the environment in a systematic manner in order to teach and strengthen desired behaviors. This method was proposed and studied by Skinner (Skinner, 1948).

Therapists who use the AAS method teach the children skills in small, measurable steps, using scientific principles to direct behavior (Richman, 2001). Verbal Behavior (VB), named for the 1957 book with the same name by B.F. Skinner, is a therapy based on four principles: requirements, contacts, repetition, and intraverbals. This technique is in fact a form of AAS, which stimulates the development of verbal communication in children through natural conditions that are applied, on average, 3-6 hours per day (15-30 hours per week), working 1:1 (one child – one therapist). Another useful technique of AAS is the Picture Exchange Communication System (PECS), a system designed to develop spontaneous nonverbal communication and stimulate spontaneous verbal expression in children with the help of photos (Coplan, 2010).

Other therapies that have been shown to be effective in the treatment of autism include work therapy, otherwise known as ergotherapy, and speech therapy, sometimes called logopaedics. Work therapy helps the patient interact with the environment through everyday productive and creative activities in order to integrate sensory stimuli in a more functional manner. Language therapy, or logopaedics, has to do with the management of speech disorders, language, communication, and swallowing in children and adults (Royal College of Speech & Language Therapists, 2014).

So far, in Kosovo, there are two basic services for autism at the governmental level: 1) the Child and Adolescent Psychiatric Clinic, which, among other services, provides diagnostic services for children with autism; and 2) a class for children with autism attached to a regular elementary school, Ismail Qemali, in Prishtina. In this attached class, integration services are provided for children with special needs, including autism, but 1:1 therapy is not possible due to the lack of human resources.

In the nongovernmental sector, there are two organizations that provide services for children with autism: the organization founded by the professionals of the National Association of Autism in Kosovo (ANAK) and by parents, "Autizmi"; and a separate organization also founded by parents, "Autizmi Flet" (Autism Speaks). In the public sector, health institutions provide free services, such as diagnostic services for children, at QKUK. However, this sector does not provide daily direct services for children with autism.

The attached class at the Ismail Qemali elementary school is the only place where children with autism are provided services on daily basis. However, this class does not have sufficient capacity to provide services for all children with autism. Alternatively, there are services provided by nongovernmental organizations, but it is a challenge for these organizations to treat children with autism due to a lack of funds. As a consequence, parents have to pay for the services they receive in these organizations.

The lack of licensed services for children with autism represents a serious problem in terms of the quality of services. Children with autism frequently receive informal unlicensed services, both legalized and illegal.

RESEARCH QUESTIONS

1. How are autistic children diagnosed in Kosovo? Does a diagnostic team take part in the diagnostic process?
2. How much are parents taking care of their children with autism limited in terms of their employment?
3. Would coverage of the costs of autism services by the health insurance scheme enable better access to these services for children with autism? Would it be sustainable?

KEY FINDINGS

- Children who have undergone the diagnostic process in Kosovo have not been diagnosed by diagnostic teams.
- Parents who have children with autism have limited employment prospects due to the need to care for their children and their inability to afford to hire assistants for this care.
- Expenses for the treatment of children with autism exceed the families' household budget and therefore significantly affect the provision of services for the children with autism, as well as endangering the ability to fulfill the families' other basic needs.

METHODOLOGY

SAMPLE

The target of this research was the parents of children age 0 to 18 years with autism. This research sample consisted of parents of children with autism who received services at the National Association of Autism and who expressed their willingness to take part in this research.

There were 42 interviews conducted with parents from the seven regions of Kosovo. Among the interviewed parents, 15, or 35.7%, were males, while 27, or 64.3%, were females. Regarding their children with autism, 61.9% were males and 38.1% were females. Of the interviewed parents, 66.7% were from the region of Prishtina, 7.1% from the region of Mitrovica, 7.1% from the region of Gjakova, 4.8% from the region of Prizren, 4.8% from the region of Gjilane, 4.8% from the region of Peja, and 4.8% from the region of Ferizaj. Of this number, 76.2% of the respondents were residents of urban areas, while 23.8% resided in rural areas.

MEASURING INSTRUMENTS

In order to test the hypotheses of this research, as well as to answer the research questions, a questionnaire package was compiled and administered containing 89 questions about:

- Demographic data
- Family socioeconomic status
- Applied diagnostic tests and procedures for children with autism
- Health services and educational/teaching services benefitting the child, and health services benefitting the parents
- Nutrition for the children
- Financial barriers
- Attitudes of respondents related to health care for children with autism
- The opinion of participants of health services in general, and health services in relation to autism in particular
- Child functioning level
- Parents'/guardians' needs in relation to children with autism.

PROCEDURE

The package of questionnaires was administered by the therapists of autistic children. Due to the complexity of these questionnaires, the therapists were trained in advance to interview the respondents.

Initially, the questionnaire was piloted to a sample of seven respondents. Based on the results from the initial sample, some changes were made in the ranking of the questions and new questions were added that were considered necessary in relation to the research aims. After these changes were made, administration of the questionnaires to the broad sample was begun. An interview lasted approximately 60 minutes. These research data have been analyzed using the Statistical Package for the Social Sciences (SPSS) software.

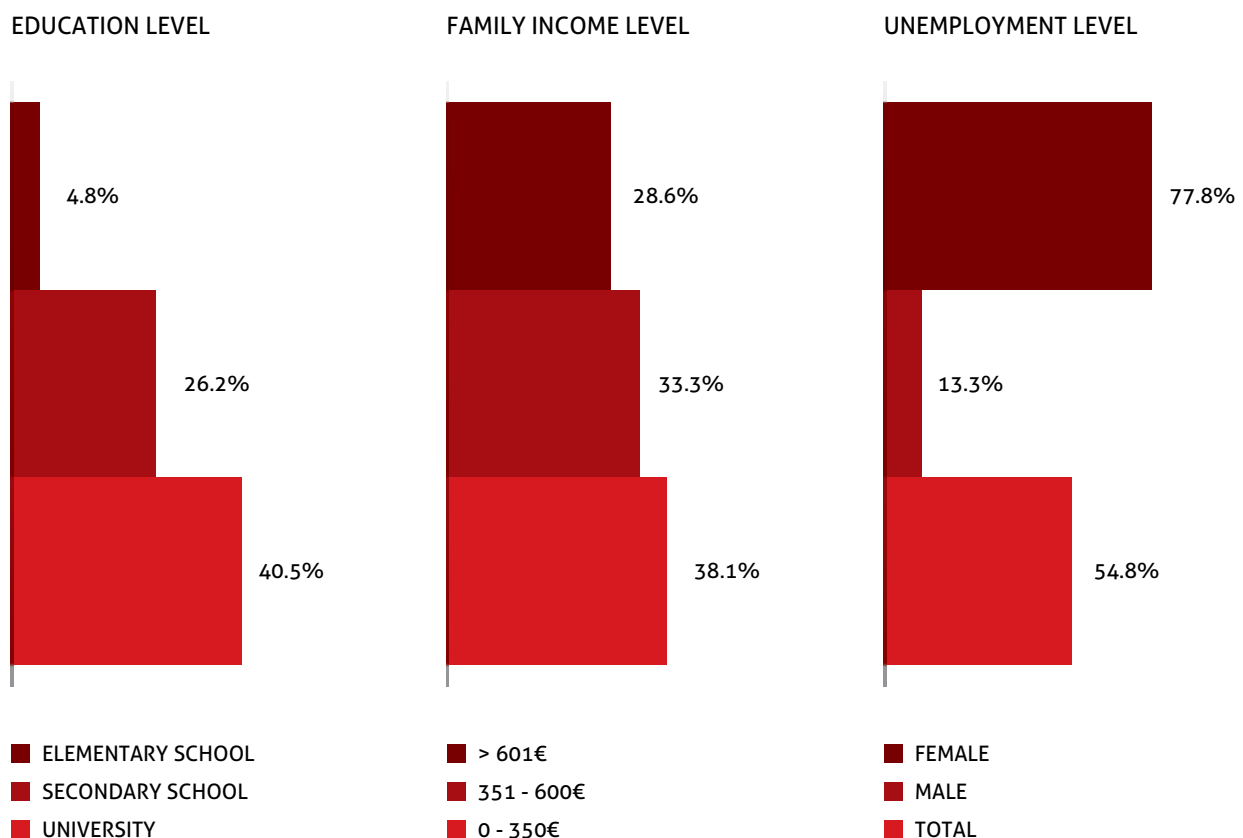
RESULTS

SOCIOECONOMIC STATUS

Regarding education levels, 40.5% of respondents reported that they had completed university and 26.2% reported that they had finished secondary school, while only 4.8% of respondents reported that they had not completed elementary school. Although a high percentage of respondents had completed university, the highest percentage was unemployed; 54.8% of respondents stated that they were unemployed. The majority of unemployed respondents were female (77.8%) compared to male (13.3%).

In terms of monthly household income, 38.1% of respondents had incomes of 0-350 euros per month, and 33.3% had incomes of 351-600 euros per month, while only 28.6% of respondents had incomes above 601 euros per month. The number of total family members among this sample varied from 3 to 10, with an average of 5.6.

FIGURE 1. Family socioeconomic status



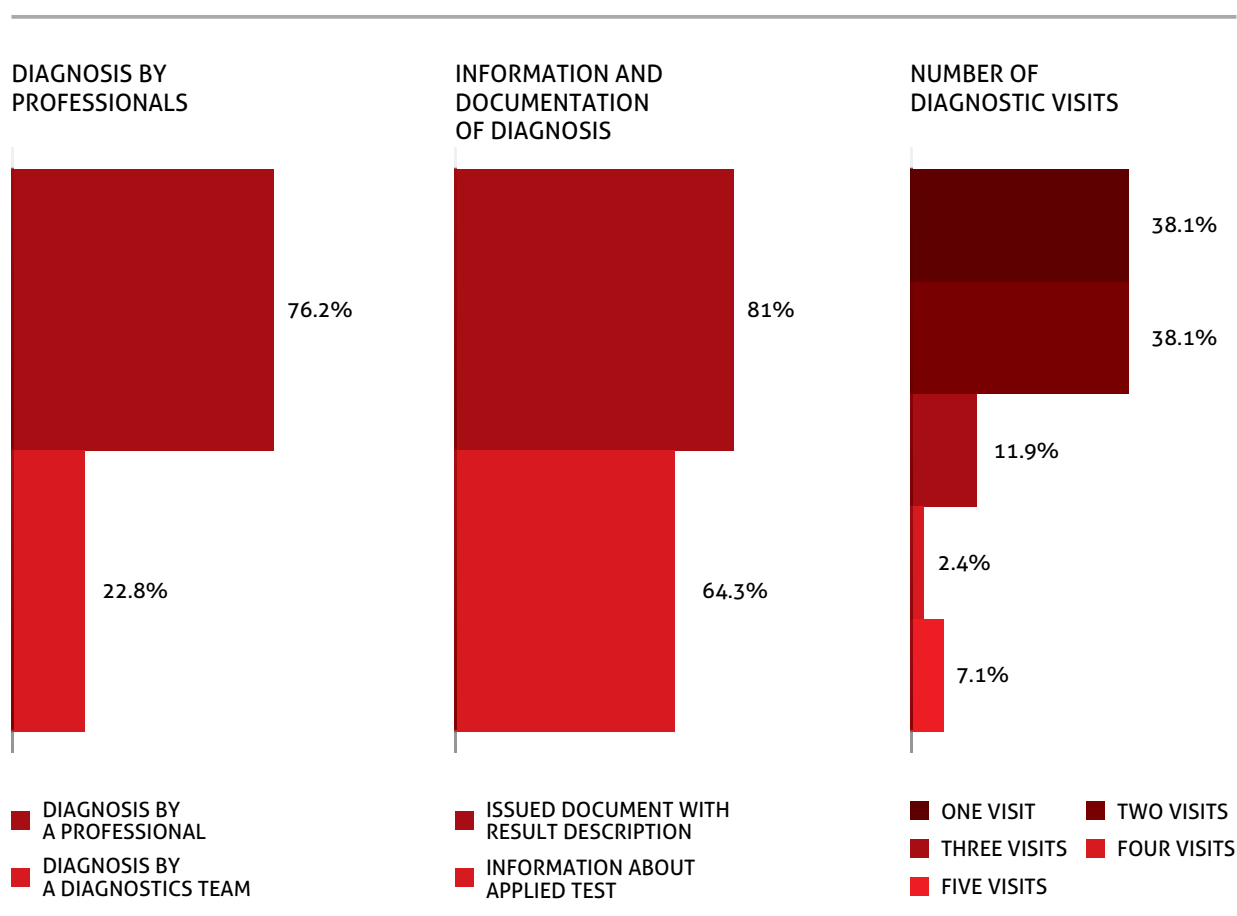
DIAGNOSIS

The findings of this research show that the age when a child was diagnosed with autism varied from the age of 2 to 11 years, with an average age of 3.9 years. Only 22.8% of the sample reported that they received a diagnosis during the diagnostic process, and that their children had mainly been diagnosed abroad, while 76.2% of the general sample stated that the diagnosis had been made by only one professional due to the lack of a diagnostic team.

In addition to the absence of an organized diagnostic team reported by the majority of respondents, 64.3% were not informed what kind of test had been applied to their children, and 96.3% had not heard of the ADOS, GARS, and CARS tests at all.

Regarding the number of visits for the determination of a diagnosis, 38.1% of respondents reported that their child had been diagnosed during the first visit, 38.1% after two visits, 11.9% after three visits, 2.4% after four visits, and 7.1% after five visits. One of the respondents reported that his child had been diagnosed after 32 visits; however, this case was complicated by affective disorder and additional problems, which required a long assessment to eliminate doubt. Of the 42 respondents that were part of this research, 81% reported that a document was issued on the occasion of their child's diagnosis, which described the results coming out of the child's assessment.

FIGURE 2. Diagnostic process



PROVIDED SERVICES AND TREATMENT TYPES

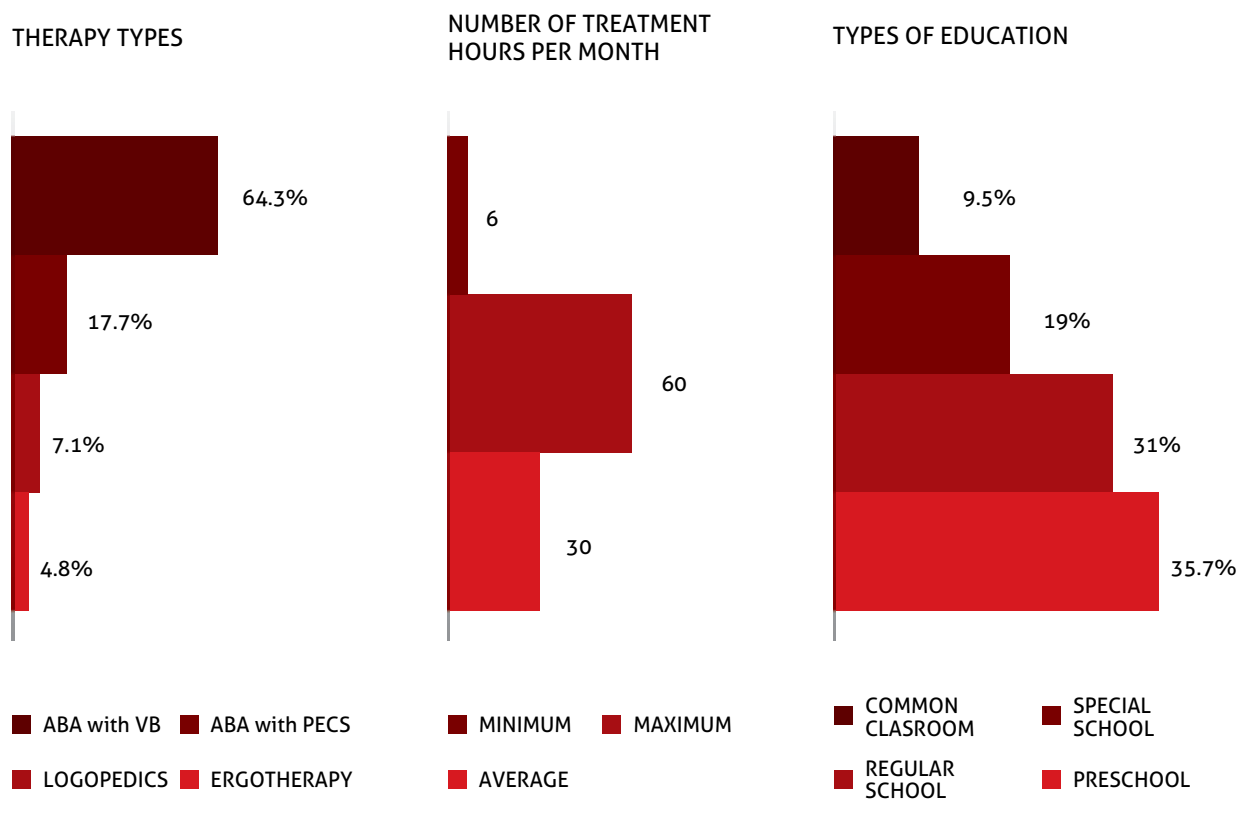
As far as necessary daily direct services for autism treatment are concerned, the questionnaire measured the levels of information and treatment for these autism treatment programs: Applied Behavior Analysis together with Verbal Behavior (ABA with VB); Applied Behavior Analysis together with communication through the exchange of photos (ABA+PECS); ergotherapy; and logopaedics. Out of 42 interviewed parents, 64.3% of them reported that their children were the beneficiaries of ABA services with VB, 17.7% were beneficiaries of ABA with PECS, 7.1% were beneficiaries of logopaedics services, and 4.8% were beneficiaries of ergotherapy. 77.5% of respondents reported that they had heard about logopaedics, while only 12.5% stated that they had heard about ergotherapy.

Average monthly costs for children with autism were 294 euros per month. This amount included only necessary services for the child with autism and transportation to the place providing the service. Due to the lack of institutional support, the money to pay for the necessary services for children with autism came mainly from the family budget. Therefore, children with autism received services only to the extent that they could be covered by the family budget. According to the sample, the average number of hours the children received services was 30 hours per month, where 6 hours per month was the minimum and 60 hours per month was the maximum.

In the absence of an institutional standard, the cost of provided services varied in different sectors. Among the organizations providing daily direct services for autism, it was found that, for beneficiaries of services from the nongovernmental sector, the average cost for 30 hours per month was 200 euros. Informal services provided outside of institutions amounted to a cost of 300 euros per month. There was a striking difference between the cost of services provided by the nongovernmental and private sectors. Services provided by professionals in the nongovernmental sector cost 200 euros for 30 hours per month, which, divided into working hours, amounted to 6.7 euros for a full working hour. By contrast, at private clinics for logopaedics, the average cost for one session (1 hour) amounted to 15 euros.

Regarding pre-primary school education, only 35.7% of respondents who had children with autism of pre-primary school age reported that their children attended these schools. Only 31% of respondents who had children with autism of primary school age stated that their children were students of regular primary schools. Among the respondents who were part of this research, only 19% stated that their children were beneficiaries of special education. Finally, 9.5% of respondents reported that their children with autism were attending the attached class at the Ismail Qemali school.

FIGURE 3. Obtaining services by children with autism



THE DIFFICULTIES OF FAMILIES WITH AUTISTIC CHILDREN

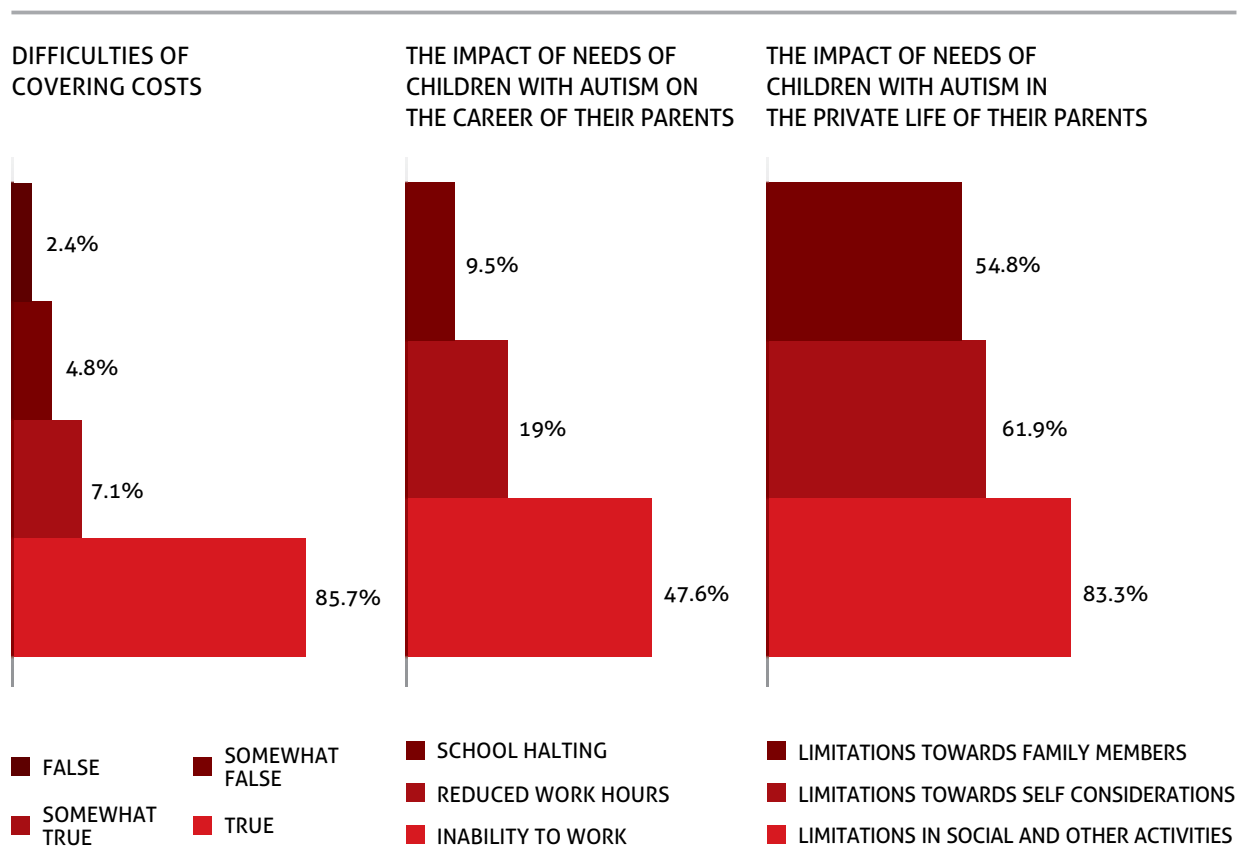
Regarding the costs to care for a child with autism, 85.7% of participants fully agreed that they had difficulties covering the cost, while only 2.4% did not consider it difficult to cover the expenses for their child's autism care, diagnosis, and treatment.

Taking into consideration the fact that children with autism have needs that differentiate them from other children, the participants were asked about the impact of these attributes on their lives. 47.6% of participants reported that, due to the specific needs of their children with autism, they could not be employed, 19% reported that they had needed to reduce their number of working hours, and 9.5% reported that having a child with autism had caused the parent to interrupt their education.

Gender differences were also analyzed as far as the perception of household work was concerned. Significant gender differences were found relating to perceptions of the importance of assistance with household work. 40% of males and 81.5% of females categorized this as very important.

Regarding the impact of a child with autism on the family, the respondents reported changes in their lifestyles such as restriction on their freedom to participate in society and activities (83.3% of respondents), restriction on the parents' dedication towards themselves (61.9%), restriction on attention to other family members (54.8%), unemployment (47.6%), reduction of working hours (19%), and interruption of schooling (9.5%).

FIGURE 4. Challenges of families with autistic children



FAMILY NEEDS OF CHILDREN WITH AUTISM

Regarding the statement *"I need to be shown that my child acting that way is different and unusual"*, 78.6% of participants reported that they considered this need to be very important, while only 9.5% reported this need was not important at all.

Regarding the statement *"I need professional support regarding proper access for my child"*, 97.6% of participants reported that they considered this need to be very important, while only 2.4% reported this need was less important.

Regarding the statement *"I need other members of the family to help me in the adequate care of my child"*, 81% of participants reported that they considered this need to be very important, while only 2.4% reported this need was not important at all.

Regarding the statement *"I need the child's peers to understand his state"*, 85.7% of participants reported that they considered this need to be very important, while only 2.4% stated this need was not important at all.

Regarding the statement *"I need to discuss my feelings for my child with other parents who have children with the same disorder"*, 73.8% of participants reported that they considered this need to be very important, while only 8% reported this need was less important.

Regarding the statement *"I need help in dealing with my fears about the future of my child"*, 95.2% of participants reported that they considered this need to be very important, while only 2.4% reported this need was not important at all.

Regarding the statement *"I need information about special programs and available services for my child and my family"*, 95.2% of participants reported that they considered this need to be very important, while only 2.4% reported this need was not important at all.

THE IMPACT OF TREATMENT ON CHILDREN'S BEHAVIOR WITH AUTISM

In order to assess the impact of treatment on problematic behaviors of children with autism (excessive crying, biting themselves or others, pinching, throwing things to the ground, etc.), the study first estimated the proportion of respondents whose children were beneficiaries of any service and those who were not beneficiaries at all. The data showed significant differences. Among the 32 participants who reported that their child was the beneficiary of at least one service, only 43.8% reported that their child had problematic behavior. Among the 10 participants who reported that their child was not a beneficiary of any service, 70% of them reported that their child had problematic behavior.

DISCUSSION

The diagnosis and treatment of autism are highly sensitive issues requiring special care, especially in terms of specifying the type of autism. Each type presents different limitations in skills, but at the same time also offers different potentials, whose identification is very important for the treatment process. Taking into consideration that children with autism do not demonstrate any physical characteristics, as well as that the diagnosis is not determined using any biological tests such as blood tests or brain scans, the diagnosis of autism in developed countries is typically made by a multidisciplinary team consisting of a psychiatrist, an ergotherapist, and a logopaedist.

Unfortunately, Kosovo lacks professionally organized teams to make these assessments, complicating not only the initial diagnosis, but also the creation of individualized, detailed treatment plans for children with autism that are adapted in accordance with the level of the child's development. However, diagnosis in the private sector or abroad is very costly, which is further exacerbated by the lack of coverage of this service through the health insurance scheme.

A team consisting of professionals of different disciplines would not only serve to provide more accurate diagnoses of autism spectrum disorders, but would also provide better treatment. Coverage of this service by the health insurance scheme would accelerate diagnosis at an earlier age, leading to more timely treatment. Although Kosovo has no professionals certified in modern methods of treatment, such as ABA with VB and PECS, in recent years there has been an increase in the number of professionals who are trained in the basic principles of these treatment methods.

Due to the absence of free services and the inability to achieve a sufficient number of daily working hours (3-6 hours) due to distance and cost, in many cases children diagnosed with behavioral problems are prescribed medications instead of getting of professional services for autism. However, these medications, which may improve or deter problematic behaviors, do not challenge the underlying problem. Despite this, there is a high likelihood that treatment with medications will be covered by the health insurance scheme as the health insurance law takes effect. ABA with VB and ABA with PECS are the most effective treatments to address the behaviors and communication problems characteristic of children with autism; therefore, we conclude that they are necessary methods to treat children with autism, in order to prevent stressing and fixations, as well as ongoing communication issues when the children reach adulthood.

Ergotherapy has special importance because of its impact on the development of the skills necessary for persons with autism and related developmental disorders to achieve an independent life. This research has found that children with autism in Kosovo are not beneficiaries of this therapy; their parents are not even informed of the importance of these treatments.

Taking into account family incomes and the number of family members, as well as the financial burden of treatment, it becomes clear that diagnosis and treatment costs present great difficulties for families who have children with autism. Another difficulty is transportation. Lack of transportation limits access to services, especially for those families who live outside the Prishtina region. Regions outside Prishtina lack professional services for autism.

Another challenge for parents is the inclusion of their children in the regular school system. It can be seen from the survey results that only a small number of children with autism are engaged in the regular school system. In addition to the challenge of school registration, a subsequent difficulty for parents to overcome is the engagement of personal assistance for the child, sometimes by the parent him/herself, in the absence of teaching assistants.

A further hardship for families with children with autism, in addition to the emotional challenges, is the impact on employment, which mostly affects unemployed mothers.

In the absence of support, especially inclusion in the regular school system, one parent is obliged to stay at home with his/her child; or the family must pay a supervisor to stay with the child. Many families face problems finding a suitable person to supervise a child with autism. This is due to the lack of trained professionals for the treatment of autism, as well as the unaffordable cost. Taking into consideration the average salary of a parent in Kosovo, if that parent has a child affected by autism, their entire salary could potentially be dedicated to the cost of supervising their child.

As can be seen from the statements of the parents, a great number of them need to be educated regarding the characteristics of autism, the typical behaviors of children with autism, and the need for proper access to care. This would help their child's progress, which would help the parents respond better to their own needs, as well as those of the child.

The statements of the parents regarding their need for help from other family members and the need for children with autism to be understood by their peers are also important indicators. Often for parents, misunderstanding of the traits of children with autism by family members and peers is a major obstacle in the treatment and progress of the children due to judgments and prejudices.

The need for each parent of a child with autism to discuss his/her concerns with other parents demonstrates the need for the organization of support groups for these parents. This type of organization is lacking in Kosovo. The only option for parents to share their concerns with others is communication with other family members and social contacts. However, these parents have social limitations due to their engagement in the care of their children with autism. This limitation further aggravates their emotional state, harming their ability to respond to the needs of their children.

According to the results of this research, in the absence of necessary services for children with autism and their parents, the parents are faced with constant fear about the future of their children. The lack of diagnostic and treatment services in Kosovo, as well as the high financial cost to cover these services, which is unaffordable for most families of these children, present numerous challenges for the families of these children.

RECOMMENDATIONS

Taking into consideration the survey findings and the state of children with autism and their families in Kosovo, this research has resulted in these main recommendations:

- Set up autism diagnostic teams, whose services are covered by the health insurance scheme.
- Make available necessary daily direct services in all regions of Kosovo.
- Include daily direct service in the health insurance package, with a basic package of 30 hours per month and a standard package of 80 hours per month; the basic package should be provided by the state, while the standard package would be paid for in part by the parent.
- Increase availability of ergotherapy and other advanced programs necessary for autism treatment in Kosovo.
- Establish daily stay centers (after receiving therapy) for children who are not integrated into the regular education system, which would enable the parents to have greater access to employment and integration in social life.
- Enable the engagement of assistants for those teachers who have children with autism in their classes.
- Organize support groups for parents free of charge under the guidance of professionals.
- Provide home services for the families of children with autism, focused on the education of all family members on autism and proper behavior towards the child with autism.
- Provide preparation and continuous emotional support for the parents regarding the future of their children.

LIMITATIONS

Because the number of participants in this research was very small, the ability to generalize the findings is limited. Therefore, the findings from this research cannot be extrapolated to all parents of children with autism. However, this research may serve as a guide for the future when the total number of children with autism in Kosovo may be statistically identified.

Also, the number of participants was limited in terms of whether or not a service was received; the process of sample selection led mainly to the identification of those that had been beneficiaries of a service. This limitation was also related to the lack of empirical data about the exact number of children with autism. Another limitation of this research was the inability to separate the sample proportionally according to the place of service and those who did not get services: in other words, there was not an equal number of participants in the sample among parents whose children were the beneficiaries of services from the National Association of Autism in Kosovo, Association "Autism," the attached class at Ismail Qemali, and those that did not receive any services from these organizations at all. This would have enabled a more accurate estimate of the costs of services and expenses.

Another limitation was the absence of literature in Kosovo on autism or important issues relating to the results of the research. The review of literature comprises only the literature of other countries.

REFERENCES

American Psychiatric Association (2000). Diagnostic and Statistical Manual of Mental Disorders (Tet Revision). Washington, DC; American Psychiatric Association.

Centers for Disease Control and Prevention (CDC). Accessed 2 December 2016 at <http://www.cdc.gov/media/releases/2014/p0327-autism-spectrum-disorder.html>

Coplan, J. (2010). Making Sense of Autistic Spectrum Disorder. Creative the Brightest Future for your Child with the Best Treatment Options. New York: Bantam books.

Elsabbagh, M. Et al (2012) Global prevalence of autism and other pervasive developmental disorders, Autism Research. Accessed 20 December 2016 at <http://onlinelibrary.wiley.com/doi/10.1002/aur.239/pdf>

Gilliam, J. E. (2006). Western Psychological Services. Accessed 29 September 2016 at

http://portal.wpspublish.com/portal/page?_pageid=53,70079&_dad=portal&_schema=PORTAL

Hendricks, D. (2013). Assessment of Screening Diagnosis and Identification of Autism Spectrum Disorder in Virginia. Virginia Commonwealth University, Autism Center for Excellence. Accessed 13 December 2016 at <http://www.vcuautismcenter.org/documents/ScreeningWhitePaper.pdf>

Lord, C., Cook, E.H., Leventhal B. L., Amaral, D. G. (2000) Autism spectrum disorders. *Neuron* 28:355–363.

Mick, K. (2005), Diagnosing Autism: Comparison of the Childhood Autism Rating Scale (CARS) and the Autism Diagnostic Observation Schedule (ADOS), Wichita State University. Accessed 13 December 2016 at https://www.researchgate.net/publication/241318309_DIAGNOSING_AUTISM_COMPARISON_OF_THE_CHILDHOOD_AUTISM_RATING_SCALE_CARS_AND_THE_AUTISM_DIAGNOSTIC_OBSERVATION_SCHEDULE_ADOS

Richman, Sh. (2001). Raising a Child with Autism. A Guide to Applied Behavior Analysis for Parents. (fq. 9-21). London: Jessica Kingsley Publishers.

Royal College of Speech and Language Therapists, (2014), Position Paper: Speech and language therapy in adult critical care, (fq.9). Accessed 13 December 2016 at https://www.rcslt.org/members/publications/publications2/criticalcare_positionpaper_060114

Skinner, B.F. (1948). Verbal Behavior, William James lectures, Harvard University, Accessed 13 December 2016 at <http://www.behavior.org/resources/595.pdf>

A photograph of a young child with curly hair, seen from behind, sitting on a chair and painting on a large white canvas mounted on an easel. The child is wearing a patterned sweater. The scene is set in a room with a wall covered in various educational posters, including one with letters and pictures (L, M, N, O, P, Q, S, Sh, T, V, X) and another with a cartoon sheep and the word 'Dele'. In the foreground, a wooden table holds a white plate, a black bowl, and a tray of paint tubes. The entire image is overlaid with a semi-transparent red filter.

ANNEX 1

	Statements of parents	Very important	Important	Not at all important
1	<i>I need to be shown that my child acting that way is different and unusual.</i>	78.6%	11.9%	9.5%
2	<i>I need professional support regarding proper access for my child.</i>	97.60%	0.0%	2.4%
3	<i>I need other members of the family to help me in the adequate care of my child.</i>	81%	16.6%	2.4%
4	<i>I need the child's peers to understand his state.</i>	85.7%	11.9%	2.4%
5	<i>I need to discuss my feelings for my child with other parents who have children with the same disorder.</i>	73.8%	21.4%	4.8%
6	<i>I need help in dealing with my fears about the future of my child.</i>	95.2%	2.4%	2.4%
7	<i>I need information about special programs and available services for my child and my family.</i>	95.2%	2.4%	2.4%



RESEARCH ON AUTISM IN KOSOVO

DETAILED MEASUREMENT OF
GROUP NEEDS THROUGH PARENTS
OF CHILDREN WITH AUTISM



NATIONAL ASSOCIATION
OF AUTISM IN KOSOVO



SOLIDAR
DUBISSE

Swiss-Libyan Association SLA