# The situation of children with autism in Shkodra city

**Zamira Shabani[1], Arben Hoxha[2], Fatmir Vadahi[3], Kujtim Pelinku[3], Rina Gera[3]**

[1]Department of Nursing, Faculty of Natural Sciences, University "Luigj Gurakuqi", Shkodër, Albania;
[2]Development Center, Shkodër, Albania;
[3]University "Luigj Gurakuqi", Shkodër, Albania.

**Corresponding author:** Zamira Shabani, MD, PhD
Address: University "Luigj Gurakuqi", Sheshi "2 Prilli", Shkodër, Albania;
Telephone: +3550684072108; E-mail: shabanizamira@yahoo.com

## Abstract

**Aim**: Autism is a group of developmental brain disorders, collectively called autism spectrum disorder (ASD). The term "spectrum" refers to the wide range of symptoms, skills, and levels of impairment or disability which children with ASD display. We conducted a review of the autism cases in Shkodra city. We described the spread of this disease by gender, place of residence, age groups and the situation of education of these children in two institutions in Shkodra city.

**Methods:** A survey point study was done among children in two institutions that provide services for all children with autism. The data collection took place in the following two institutions in Shkodra city: "Development Center of Children" and "Special School". A descriptive method was used in the current review work.

**Results:** Overall, there were 49 children diagnosed with autism who followed their studies in these two institutions (34 children attended the "Development Center of Children" and further 15 the "Special School"). This study has evidenced that males were more affected than females (79% males vs. 21% females). The vast majority of cases were from urban areas (86%).

**Conclusions:** Our study provides evidence on the distribution of children with autism in Shkodra city, an under-researched topic in Albania which deserves robust investigation. The available evidence indicates that the problem of autism is not well-known in this region of Albania. The Albanian health system faces considerable challenges regarding the diagnostic and treatment capacities of this condition which also poses a serious burden to families of the affected children.

**Keywords:** autism, children, health, mental.

## Introduction

Autism is a group of developmental brain disorders characterized by difficulties in social relations and communications and by rigid patterns of behavior among the affected individuals (1). In a 2009 government survey on autism spectrum disorder (ASD) prevalence, the Centers for Disease Control and Prevention (CDC) found that the rate of ASD was considerably higher than in the past US studies. Based on health and school records of 8-year-olds in 14 communities throughout the country, the CDC survey found that around 1 in 110 children had ASD (2). Boys face a risk four to five times higher than girls. It is estimated that about 1 in 400 individuals exhibits the symptoms of the core syndrome of autism, whereas 1 in 100 individuals falls into the autism spectrum.

People with an autistic spectrum disorder have difficulties in: social interaction, communication (both verbal and non-verbal), are restricted, exhibit repetitive interests and behavior and they have abnormal development before the age of 36 months (Table 1). Children in the autistic spectrum often make poor use of interpersonal social cues, e.g. facial expression, eye gaze, social smiling and gesture. Such children show a lack of awareness of, or an unusual response to, other people's feelings and, sometimes, to their own feelings.

**Table 1. Early Symptoms of Autism (3)**

| Social behavior | Typically develops | Behavior in children with autism |
|---|---|---|
| Looking at faces | Birth | Less at 12 months |
| Following person's gaze | 6–9 months | Less at 18 months |
| Turning when name called | 6–9 months | Less at 9 and 12 months |
| Showing objects to others | 9–12 months | Less at 12 months |
| Pointing at interesting objects | 9–12 months | Less at 12 and 18 months |
| Pointing to request | 9–12 months | Not delayed at 18 months |
| Symbolic play | 14 months | Absent at 18 months |

The affected children find it difficult to develop relationships with other children, especially when they are young, and can appear disinterested in other children and adults, or only maintain interaction for a short period. Commonly, they become more sociable with age. Their behavior is often socially inappropriate, with little understanding of social rules.

The epidemiology of ADSs is difficult to determine, because of the diagnostic dilemmas and will depend on the diagnostic boundaries. Most recent evidence gives estimates of an autistic spectrum disorder in a preschool population of 45.8 per 10,000 (1). A study of Asperger's syndrome gives a rate of 36 to 71 per 10,000 population. Severe classical autism is thought to affect around 6 to 9 individuals per 10,000 individuals of the population. ADSs are diagnosed much more commonly at present days than in the past, probably because of increased recognition and awareness, rather than a true increase in the incidence. There are no marked variances within social classes or ethnic groups. Males are affected more than females at an approximate ratio of 4:1 for classical autism, and at a ratio of 9:1 for Asperger's syndrome (4).

The diagnosis of ASD is complex, and involves an in-depth assessment. Various diagnostic tools have been developed, including the ADI (Autism Diagnostic Interview), the ADOS (Autism Diagnostic Observation Schedule), or DISCO (Diagnostic Interview for Social and Communication Disorders) (5).

As a screening tool for use in young children, the Checklist for Autism in Toddlers (CHAT) has been designed for use by GPs and Health Visitors. This is a quickly administered questionnaire in order to screen for the presence of autistic traits at a very young age during routine clinic visits. Specialist clinics will often have assessment protocols, including clinical opinions from a psychologist, speech therapist, pediatrician, psychiatrist, occupational therapist and so on. If the child is in an educational setting, observations from teachers and other staff will be sought, as these children's difficulties often come to light in these settings, initially as 'non-conforming'. In practice, some children are not diagnosed until junior or senior school. This is often regrettable, as intervention at an early age can lessen

the impact on the child and family's life. There are four basic goals of management (6): fostering social and communicative development, enhancing learning and problem-solving, decreasing behaviors that interfere with learning and access to opportunities for normal experiences, helping families to cope with autism.

Psychological interventions, e.g. ABA (Applied Behavior Analysis), PECS program (Picture Exchange Communication System), and TEACCH program (Treatment and Education of Autistic and related Communication-Handicapped Children) have been widely used and focus on communication and behavior.

## Methods

This was a descriptive study conducted in Shkodra city, which is the largest city in North Albania. We included all cases diagnosed with autism pertinent to the following two institutions: "Development Center of Children" and "Special School".

The "Development Center" is a part of the "Social Service", whereas the "Special School" belongs to the Ministry of Education. The "Development Center" is a center divided into two parts: the day Care Center and the Residential Center. The Center provides services for all children with disabilities, but at the same time they treat the autistic children too. The center has 58 children at the daily care center and 48 resident children which get therapeutic services by psychologists, social workers and special educators. Children receive different therapies such as: Speech Therapy, Physiotherapy, ergo therapy and musical therapy. The methods used by the special educators are LAP and BAP. ABA therapy is used only by the therapists who know and apply it, while other therapists use their techniques and methods according to their specialties including: psychologist, ergo therapist, logopedist which have specific fragments of work with these children. Each of these professionals applies their own methods as an aspect of the peculiarity of his/ her work. Ultimately, they form a working group that should work with these children. ABA therapists certified may be persons without titles and degrees, but may have only secondary education. ABA therapy is a working methodology that actually occupies the most time in their treatment. The ABA therapy occupies 20-40 hours per week, which makes it very expensive. Ideally, autistic children should go to kindergartens and public schools with other "normal" children. During the classes, these children should be supported by a supporting teacher who should interact with the class teacher. However, this is not currently the case because there are no special programs in the field.

"Special School" is the other institution where the autistic children take their daily therapy. Nevertheless, the staff is not qualified for this group of children. The age group that is treated in this school is between 7-16 years old and the teaching methods used are the same as those in the "Development Center".

In our study, the distribution of cases of autism was presented by the age of children, gender and place of residence. Excel (Microsoft Office, 2007) was employed to depict the distribution of the cases of autism by socio-demographic variables of the affected children.

## Results

Overall, there were 49 children diagnosed with autism attending their studies in both of these institutions (34 children attended the "Development Center" and 15 further children the "Special School"). Our analysis revealed that males were more affected than females (79% males vs. 21% females) (Figure 1).

The age-group most affected was 7-16 years with 65% of the cases (Figure 2). Males were most affected in both age-groups, as evidenced in Figure 3. The largest number of the cases diagnosed with autism was from urban areas (86%), as shown in Figure 4.

Overall, the incidence rate of autism in Shkodra was 1.99 cases per 10,000 individuals of the population. It should be pointed out, however, that the situation may be far worse because the diagnosis of autism is not easy to conduct for the parents, educators and family physicians.

**Figure 1. Distribution of autistic children according to gender**

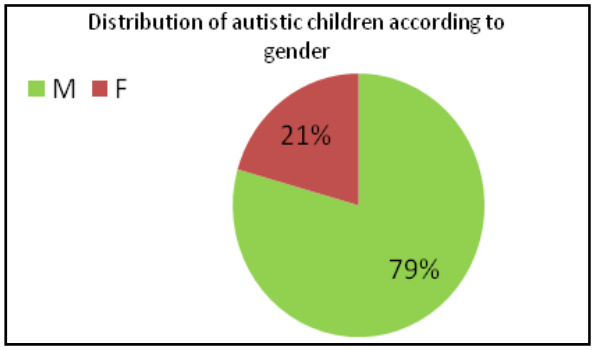



**Figure 2. Distribution of autistic children according to age-group**

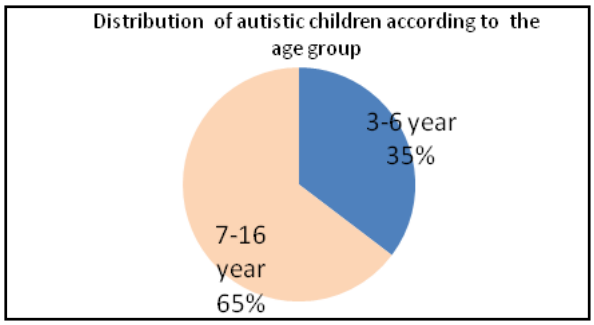



**Figure 3. Distribution of autistic children according to gender and age-group**

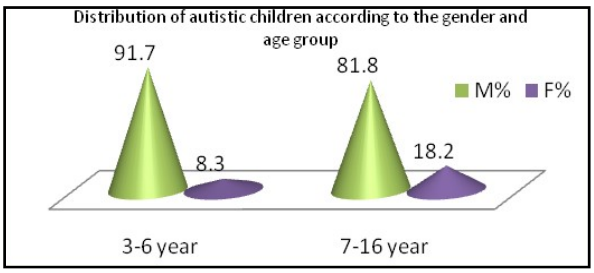



**Figure 4. Distribution of autistic children according to their residence place**

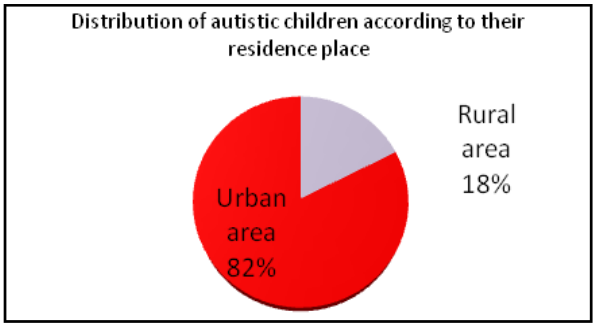
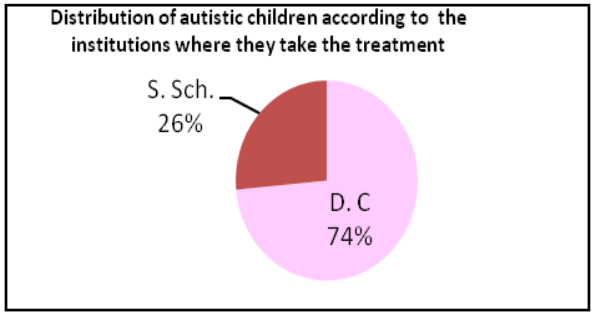



**Figure 5. Distribution of autistic children according to the institutions where they take the treatment**




## Discussion

ASD represents a big problem especially in developing countries which have not developed yet the capacities of proper diagnosis, treatment and rehabilitation of the children affected by this disorder. Despite the high burden of autism and other developmental disorders in children and adolescents, these conditions have been widely neglected by policy makers and public health experts, particularly in low- and middle-income countries. As a consequence, children and families in need have often poor access to services and do not receive adequate treatment and care (7).

In the International Day of Autism, 2nd April 2012, in Albania, no official data about the number of children affected by autism were declared. But, this year the doctors have released an alert emphasizing that this disease has increased during the past 10 years. They confirm that in 160 children born in Albania 1 of them is affected by autism. Until the end of 2008, there were counted about 4300 children and adolescents diagnosed with autism. However, these data are not officially confirmed.

In Albania the children with autism are diagnosed by the National Diagnostic Center of Autism in Tirana city and in other parts of Albania by neuropediatricians in regional hospitals. Indeed, the number of children with autism has increased during the last years. This alert is claimed by many countries of the world and, in this framework, it should be mentioned the report of ASA (Autism Society of America). According to this report, the incidence rate of autism from 1 in 150 children 10 years ago, raised currently to 1 in 88 children with autism. The data of this report are approximately the same with those in Albania, too. The number of children with

autism has increased. This confirmation is based on researches carried out in specialized centers for their treatment in public and private educational institutions. The first steps of diagnosis begin with the representation of the first symptoms by the parents at the physician or family doctor. The family doctor necessarily asks help from a neuropediatrician to make further assessment of "critical points" which include: child behavior, or the communication and the relation of child with other persons. In order to make a more specific assessment of the symptoms of autism in Albania, currently it is established the National Center of Rearing, Development and Rehabilitation of Children in Tirana. This center has a qualified staff with doctors and therapists who make possible the monitoring, evaluation, provision of accurate diagnoses and appropriate therapies for their treatment for short and long periods. Children are presented with behavioral and emotional problems in primary care, in schools, to primary care staff, GPs, health visitors and school nurses.

Several documents have emphasized the importance of early intervention and the importance of supporting and developing the skills of the staff working in the primary health care. Nurseries or schools are the most obvious settings from which such information may be collected. However, the degree to which information from teachers and schools helps in accurate diagnosis has not been well tested (8). The stigmatization and discrimination associated with these illnesses also remain substantial obstacles to diagnosis and treatment. The absence of ADSs and other mental disorders among children from lists of the leading causes of death has contributed to their long-term neglect by both public policy-makers in developing countries, as well as donor agencies (9).

The intention is to prevent problems from becoming more serious and more difficult to treat. Good and appropriate education, addressing behavioral problems and providing family support can contribute to a better prognostic outcome. People with ASD are often quite skilled at working on computers. At the moment, there is still insufficient provision for children on the autistic spectrum, and little understanding of them as adults out in the wider community. Mental health disorders such as the ASDs have potentially long term effects on adult mental health. Individuals may respond to poor mental health by engaging in risky behaviors (consumption of drugs, cigarettes, alcohol and cannabis) and by school drop-out. In addition to any direct effect, these behaviors might have a negative impact on school performance, or may gradually impair mental capacity of the affected individuals. As a matter of fact, the mental distress is strongly associated with poor educational outcomes and early drop-out (1).

The 133rd Executive Board adopted a resolution on "Comprehensive and Coordinated Efforts for the Management of ADSs" on May 30th 2013. The resolution urges Member States to increase the capacity of health and social care systems to provide services for individuals and families with ADSs and other developmental disorders. It highlights the importance of implementing resolution WHA 66.8 on the comprehensive mental health action plan 2013–2020, as well as resolution WHA 66.9 on disability, in order to scale up care for individuals with ADSs and other developmental disorders and as an integrated component of the scale-up of care for all mental health needs (10).

The Department is planning a consultation on ADSs and other developmental disorders: From awareness Raising to Capacity Building. It aims to identify priorities for action and effective strategies for strengthening capacities in countries and promote the establishment of a global network. The meeting will bring together high-level stakeholders, policy makers, experts from relevant disciplines, civil society, international organizations and NGOs (10).

## Conclusions

Overall, in Shkodra city there were 49 children diagnosed with autism that pursue their studies in two institutions (34 children attend the "Development Center" and 15 attend the "Special School"). This study has evidenced that males were more affected than females (79% male vs. 21% females). The most diagnosed cases were pertinent to urban area (82% vs. 18% in rural areas). The estimate incidence of autism in Shkodra was 1.99 cases per 10,000 population. However, this may be under-estimated due to difficulties and challenges related to the reporting of the cases with autism.

Children on the autistic spectrum should be educated in many different settings, depending on their needs ranging from special schools for autistic children and other special schools, to mainstream schools. All these steps need a strong and sustainable financial support though.

In conclusion, our study provides evidence on the distribution of children with autism in Shkodra city, an under-researched topic in Albania which deserves robust investigation. The available evidence indicates that the problem of autism is not well-known in this region of Albania. The Albanian health system faces considerable challenges regarding the diagnostic and treatment capacities of this condition which also poses a serious burden to families of the affected children.

**Conflicts of interest:** None declared.

## References


1. Child and Adolescent Mental Health, Theory and Practice. Problems in young children Autism spectrum disorders 2005:104-109.
2. Prevalence of autism spectrum disorders - Autism and Developmental Disabilities Monitoring Network, United States, 2006. MMWR Surveillance Summaries, 2009 Dec 18;58(10):1–20.
3. Mash JE, Barkley AR. Child Psychopathology 2th Edition; 2003. Autistic Disorder. Pg. 410.
4. Attwood T. Asperger's syndrome: A guide for parents and professionals. London: Jessica Kingsley; 1997.
5. Wing L. The autistic spectrum: a guide for parents and professionals. London: Constable and Robinson; 1996.
6. Rutter M, Taylor E, eds. Child and adolescent psychiatry. Oxford: Blackwell Science; 2002.
7. World Autism Awareness Day: 2 April 2012. http://www.who.int/mental_health/prevention/childado/en/.
8. Autism diagnosis in children and young people: Recognition, referral and diagnosis of children and young people on the autism spectrum. Issued: September 2011, pg 33. NICE clinical guideline 128. http://www.guidance.nice.org.uk/cg128.
9. Need to address mental disorders in children. WHO calls for action on World Autism Awareness Day, *2 April 2009, Geneva.* http://www.who.Int/mediacentre/news/releases/2009/autism_children_20090402/en/.
10. EB resolution on "Comprehensive and Coordinated Efforts for the Management of Autism Spectrum Disorders".http://www.who.Int/mental_health/action_plan_2013/eb_resolution_childhood/en/.