



**DECENNIAL REPORT**  
OF NATIONAL  
ASSOCIATION OF AUTISM  
IN KOSOVO (**ANAK**)

APRIL 2022



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## OPENING WORD



### JETA DEVA

MR. SPEC CLINICAL  
PSYCHOLOGIST  
EXECUTIVE DIRECTOR

*April 2022 marks a decade since ANAK was established and initiated work with providing direct therapeutic services for children with autism in Kosovo. It has been ten years of sacrifice, tireless work, passion and unwavering dedication of the entire staff in achieving the best of results. But it has also been ten years filled with joy, hope and motivation, which stem from tens and hundreds of children, whose lives have changed and continue to change for the better.*

ANAK began at a time when autism in Kosovo faced multifaceted and multi-layered problems, which made the work extremely difficult. The lack of social awareness, stigma attached to persons with autism, lack of supportive educational services for children with autism in schools, lack of state investments in providing quality services, among others, are problems with which ANAK has dealt since its first day of establishment. But these were exactly the foundation of our motivation and dedication to push things forward, to include as many children with autism as possible in therapeutic services and school, so that no child with autism is left behind without receiving the necessary and quality service. This fight is still ongoing.

For ANAK, this has been a ten-year journey of learning, where we had the privilege of immersing into the beautiful world of autism, seeing children mutter their first words, becoming able to communicate and gaining some independence over their lives. Ultimately, every effort, every sacrifice is a reward when you see a child utter his/her first word.

Naturally, all of this would have been impossible without the engagement and commitment of parents of children, who, throughout the years, have had the full trust of ANAK and have shown their determination to follow professional advice, and to continue the therapeutic methodology in their families.

Despite all the challenges and difficulties, ANAK is stronger and more sustainable today than ever before. Public institutions, various donors, private businesses, but also individual supporters have come to the aid of ANAK. And for this we are forever grateful. They are all contributors to ANAK's success today.

## NATIONAL ASSOCIATION OF AUTISM IN KOSOVO

National Association of Autism in Kosovo – ANAK, is a nongovernmental organization established in January 2012 with the support of professors of the Department of Psychology and Education, through which the provision of individual services for children with autism was enabled, based on primary principles of behavior therapy and verbal therapy, as well as systematic training of families of those children.

Since its establishment, ANAK's unwavering priority has been the quality of individual therapy, with the focus of intervention based on principles of therapy of Applied Behavior Analysis and Verbal Behavior, methods scientifically proven to be successful. Apart from direct therapy for children with autism, therapists report verbally on daily basis to parents of children, supervise development of children, review priorities of needs of children, as well as enter data in the internal system E-Data in a longitudinal manner.



ANAK IN 2012



ANAK IN 2022

In order to implement and link the chain of needs that a person with autism and his/her family has, ANAK has constantly provided: developmental clinical assessment, individual work plan,

trainings for parents based on the individual work plan, daily direct professional service, regular consultation with parents, as well as consultation with teachers in schools, in cases when a child has managed to integrate in the regular education system.

Apart from direct professional services, ANAK has, since its establishment, contributed systematically in social awareness on autism and unique abilities and skills that may be associated with it, thus propagating an awareness mentality which does not victimize. Furthermore, ANAK has continuously made efforts in influencing and promoting voluntarism, as well as institutional advocacy in the fight for the rights of persons with autism and their families.

ANAK continues to ensure its sustainability mainly from minimal contributions of parents and the professionalism of its staff, and on the other hand, thanks to the help of different donors, it manages to cover some expenses and provide additional and free of charge services for children in the center.

## VISION & MISSION

### A SOCIETY WHICH ENSURES QUALITY LIFE AND FULL RIGHTS FOR PERSONS WITH AUTISM

#### VISION

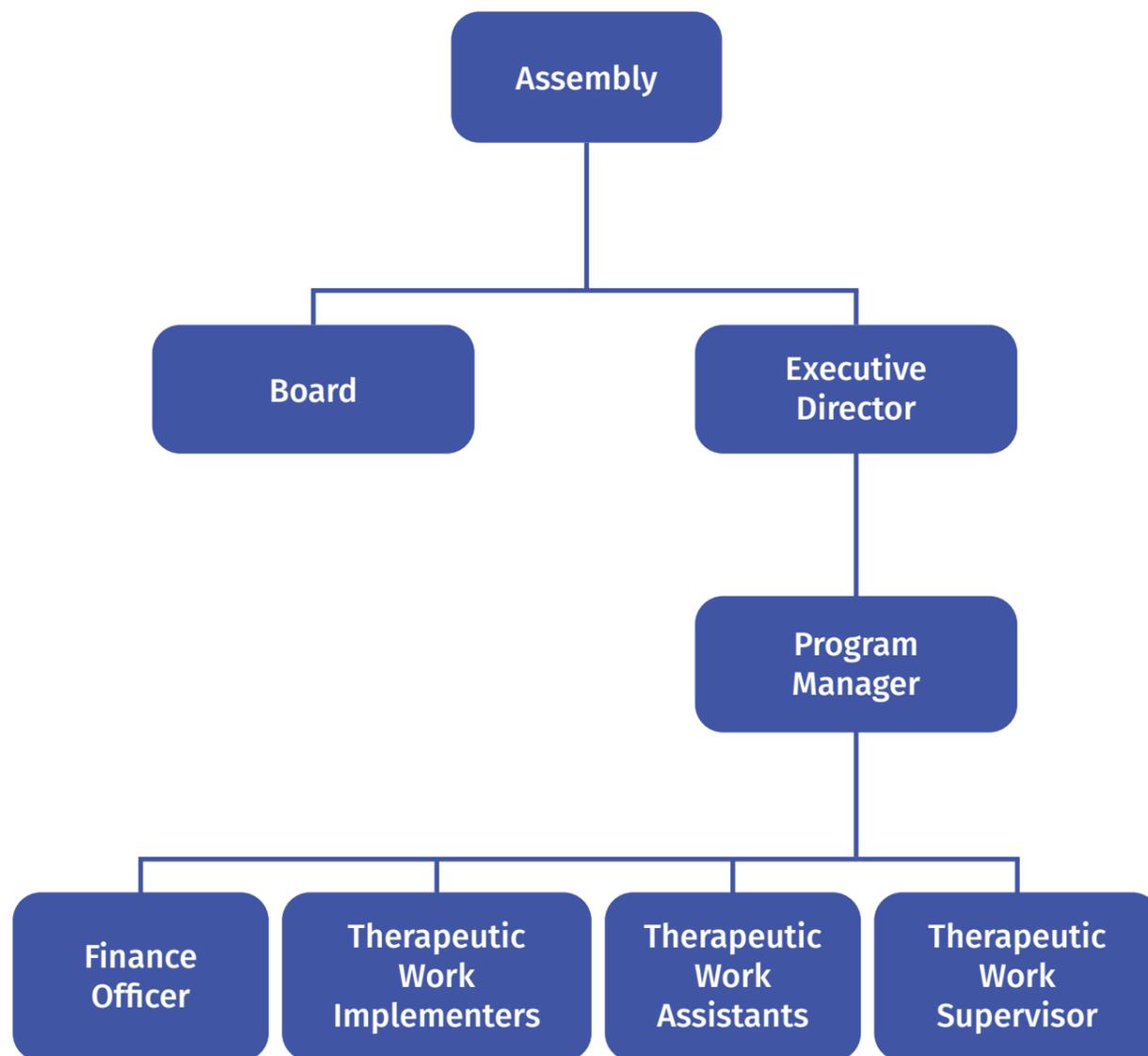
ANAK's vision is to provide a systematic and qualitative contribution in creating favorable and appropriate conditions for persons with autism, so that they receive the services they need, and to contribute that persons with autism enjoy the rights and opportunities all the other members of society do. ANAK will work for a future where all persons with autism receive daily professional services and are accepted and respected in society.

#### MISSION

ANAK aims to fulfill its mission through: providing direct professional services (assessment, daily direct services, professional consultations, etc); comprehensive inclusiveness (assistance in integrating children with autism in the education system and social system in general); providing trainings (organizing trainings and workshops for professionals and parents of children with autism); translations (continuous translation of literature on autism, working methods used when working with autistic cases and other relevant materials related to autism); research (continuous research

on the number of persons with autism, existing and necessary services, as well as other issued related to autism); publications (publication of reports on annual basis and other important materials on autism); awareness campaigns (media conferences, leaflets, documentary films, etc.); advocacy (cooperation with relevant institutions in governmental and non-governmental level on building capacities for services for autism) and other relevant activities.

## ORGANIZATIONAL STRUCTURE



## Council of ANAK

- 1 **MIMOZA GASHI**, Master's degree and Psychology Specialist, co-founder of ANAK, with an experience of 17 years in professional trainings
- 2 **AFËRDITA GOÇI**, Child and adult psychologist, with an experience of over 18 years as psychiatry specialist, co-founder of ANAK
- 3 **JETA DEVA**, Master's in psychology and Clinical Psychology Specialist, co-founder of ANAK and Executive Director, with an experience of over 17 years in treating autism
- 4 **VIGAN BEHLULI**, Master's degree and Clinical Psychology Specialist, with an experience of over 18 years in research and several years of experience in psychotherapeutic interventions
- 5 **VLORA ISUFI**, Psychologist and former supervisor of therapeutic work at ANAK, with an experience of over 8 years with children with autism

## Board of ANAK

- 1 **MOSHE LANDSMAN**, PhD, co-founder of Psychology Department of University of Prishtina and Professor of Psychology at UP since 2001.
- 2 **ARIANA SHALA**, Master's degree and Clinical Psychology Specialist, Chairwoman of Board of ANAK, with an experience of over 17 years in psychotherapeutic interventions
- 3 **ALIRIZA ARËNLIU**, PhD, co-founder of Psychology Department of Prishtina University and Professor of Psychology at UP since 2001.

## Key Staff

ANAK's Executive Director has a supervisory role of all services provided by the organization, and is responsible for the overall flow of work of the organization in general. The executive director, among other things, has the role of promoting the work of the organization and fundraising, which enable the provision of services free of charge for children with autism and their families, as well as treating autism in all levels.

Almost all the staff employed at ANAK is mainly engaged in implementing the daily therapeutic work during daily direct services. In addition to leading therapists, ANAK also employs assistants, who support the work with daily therapeutic services. Continuous intervision among professional staff and the supervision of methods used are an inseparable part of the entire therapeutic process at ANAK.

The dynamic and noble work of ANAK personnel has enabled the organization to maintain its strongest weapon 'preservation of quality of individual work', based on limited data, but with tangible results. Challenging problematic behavior of children is achieved based on the faith of ANAK therapists in the clear effect of methods of Behavioral Analysis. Recognizing unique capacities of children with whom we work, only further stimulates the persistent sustainability of professional work at ANAK.

## Strategic operative objectives of ANAK

### STRATEGIC OBJECTIVE I: PROVISION OF DIRECT PROFESSIONAL THERAPEUTIC SERVICES

Provision of individual professional direct therapeutic services for persons with autism and their families, in order to contribute in filling the institutional gap and concretely improving the quality of life for persons with autism and their integration in society, especially by focusing on integration in school institutions which children with autism attend.



### STRATEGIC OBJECTIVE II: INTEGRATION AND INCLUSIVENESS

ANAK serves as a connecting bridge between kindergartens, schools and children with autism and their families, working preliminary with children so that they are ready for integration in the regular education system. ANAK continuously works towards maintaining and establishing new cooperations with staff in various institutions, based on relevant applicable regulations, with the aim of protecting rights of children with autism and their integration and inclusion without discrimination.



ANAK also contributes to capacity building of educators and teachers in kindergartens and schools regarding autism, by focusing specifically in using adequate and effective methods in treating and supporting children with autism.

### STRATEGIC OBJECTIVE III: **ADVOCACY**

Having in mind that the incidence of autism in the world is 1 in 110 children, and having in mind that lacking of individual services for those children, it is paramount that advocacy is further advanced for basic packages as part of essential public services. By 2023, ANAK aims to have covered assessment for every child regarding their development, individual plan, regular weekly sessions for each child and trainings for each family. ANAK's objective is to ensure inclusiveness and access to services for all children, reducing thus discrimination on economic and social basis.

ANAK has carefully reviewed the Draft Law on Assessment, status acknowledgment, benefits and services for persons with impaired abilities, and has presented recommendations during its drafting. Nevertheless, it is paramount to have nation-wide advocacy efforts together with other organizations, which have identified challenges that children with autism and their families face, and the needs they have. With the approval of this law in the Kosovo Assembly, the financial burden of families would be greatly reduced, providing thus possibilities for choosing quality service and opportunities for employing family members of those children. On the other hand, educators and teachers would have a stable and sustainable support from assistants supported by public institutions.

ANAK considers that autism must be the focus of efforts in tackling unequal rights and undertake serious efforts in implementing health insurance, an issue on which ANAK has advocated in partnership with Solidar Suisse for years and years. Furthermore, it is also necessary to undertake concrete planning for the transition of services for adults with autism, through oriented integration in the community.

### STRATEGIC OBJECTIVE IV: **EDUCATION**

ANAK's aim is to educate future professionals on autism through organizing trainings for students of psychology, education and speech therapy. ANAK also aims to establish a

system of professional supervision and their practical work.

Through regular media presentations and increased visibility, ANAK will continue to exert its impact on increasing awareness on autism to a large part of society, including here regular discussions in schools with students and teachers, as well as through different awareness campaigns.

Furthermore, ANAK will continue to collect data on children's progress, and in cooperation with various researchers in social and scientific fields, establish a bedrock, wherewith the use of various working methods stemming from findings in the Kosovo context, especially in success stories, are more reliable for motivation.

### STRATEGIC OBJECTIVE V: **EFFECTIVE AND EFFICIENT MANAGEMENT OF THE ORGANIZATION**

Among different challenges, ANAK concludes that effective and efficient management is a precondition for a proper functioning of the entire organization, including provision of services or advocacy on advancing rights of persons with autism. Therefore, ANAK plans to increase its efforts in treating this issue, be that through increase of human resources dedicated for this part of work, but also through an increase of capacities of other staff for specific managerial tasks. This will go hand in hand with advancing of internal documents and work practices, aiming at clarifying responsibilities and increasing efficiency of work in general.

Data entry for systematic measurement of progress of therapeutic process in E-data plus program is carried out through continuous supervision on each step of each objective from individual plans of each child. This program is maintained by Dr. Neil Martin, director of international development of the Board Certified Behavior Analyst (BCBA). Collected data in the program are used by the organization for analysis of initial state and results achieved from work with each child receiving different services from the organization.

### STRATEGIC OBJECTIVE VI: **SUSTAINABILITY**

ANAK continues to ensure its sustainability mainly through minimal parent contributions and the professionalism of its staff. Furthermore, through organizing different campaigns

which include creation of artworks from children with autism and their sale, ANAK ensures symbolic revenues which are used for the functioning of the organization and provision of services for children with autism and their families. Additionally, ANAK receives some support from private businesses in Kosovo, which regularly contribute financially to the organization, helping thus provide essential services for children with autism and their families.

ANAK regularly advocates and lobbies for the need of supporting persons with autism, by providing a sustainable system of social services; financial and social support for families of children with autism; establishment of adequate working environments for children and adults with autism; as well as increasing capacities of educators and teachers, so that they provide professional support for children with autism.

ANAK continuously submits applications to various potential donors for financial support in implementing different programs and projects which would contribute in improving the situation of persons with autism and their integration in society, as well as in providing support to parents of children with autism, who are also key parties in improving the situation of their child as well as integrating their children in society.

## GENERAL INFORMATION ABOUT AUTISM

Autism is a neurobiological disorder which is characterized with difficulties in communication, social interaction and repetitive behavior, and a narrow range of interests. Starting from an early age, persons with autism face challenges directly related to difficulties in communication, which may stem from the development of problematic behavior as the child is unable to understand others' perceptions. The situation worsens when the child reaches adolescence, thus increasing his/her demands with persistent behavior towards realizing demands.

Despite the fact that the education system in Kosovo is mandated to implement law No. 04/L-032 on Pre-University Education in the Republic of Kosovo for the integration of children with autism within the regular education system, parents of children with autism systematically have challenges in the process of integrating their children, beginning with the practical problem of lacking individual assistants on regular basis. Lacking economic means to pay assistants, parents seldom are forced to suspend schooling for their children, or assist their children in class themselves. This is a reflection of a symbolic solution of the state in relation to the law, where it provides rights but still does not provide sustainable institutional solutions.

### SOME OF THE CHALLENGES AND DIFFICULTIES THAT CHILDREN WITH AUTISM FACE ARE AS FOLLOW:

#### A) DIFFICULTY IN SOCIAL INTERACTION

- Difficulty in social interaction
- Lack of interest to develop friendships with others;
- Lack of eye contact;
- Lack of expression of joy, success or their achievement to others;
- Different perception of understanding emotional states of others, such as: joy, pain, humor, play etc.

#### B) DIFFICULTY IN COMMUNICATION

- In some cases, they are characterized with delays in speaking or the child has said some words but around the age of 2-3 years, they stop repeating them;

- Lack of initiative to start conversations or ask questions;
- Seldom lack of verbal communication in using meaningful words, or difficulty in non-verbal communication of their needs to others, i.e. body language;
- Lack of interest in accepting requests of others;
- Repetition of words out of context, such as words out of a tv advertisement.

### C) REPETITIVE BEHAVIOR AND EMPHASIZED INTEREST IN SPECIFIC THINGS

- Repetitive body movements, such as clapping/shaking hands, spinning objects, play with fingers, spinning around themselves etc;
- Fixation with letters, numbers, parts of objects, lining objects/colors etc;
- Repetition of same sounds;
- Detailed focus on things around them, skipping their function entirely;
- Emphasized need for sameness and routine – stopping by the same shop, walking through the same road, listening to the same part of a song/video, etc.

## Perceptions regarding persons with autism

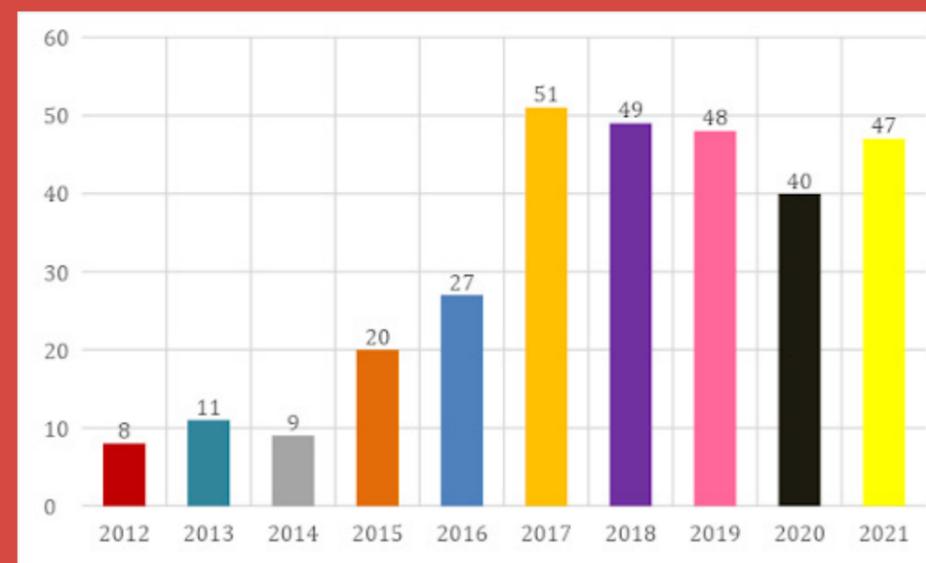
It is fairly obvious that persons with autism do not differ in physical features from persons with typical development, and very often misunderstandings arise in communities when they are faced with unusual behavior. Because the autism specter is characterized by a variety of types, with its elements varying in degree from one another, generalizations are made regarding capacities or behaviors of persons with autism. For example, persons with autism who are high functioning and have high intelligence have been excluded from inclusion in activities because they were prejudiced on their non-typical behavior. On the other hand, persons who have a more noted density of autism elements and who have not developed verbal communication at all, are prone to being victimized by the community.

## Employment opportunities for persons with autism

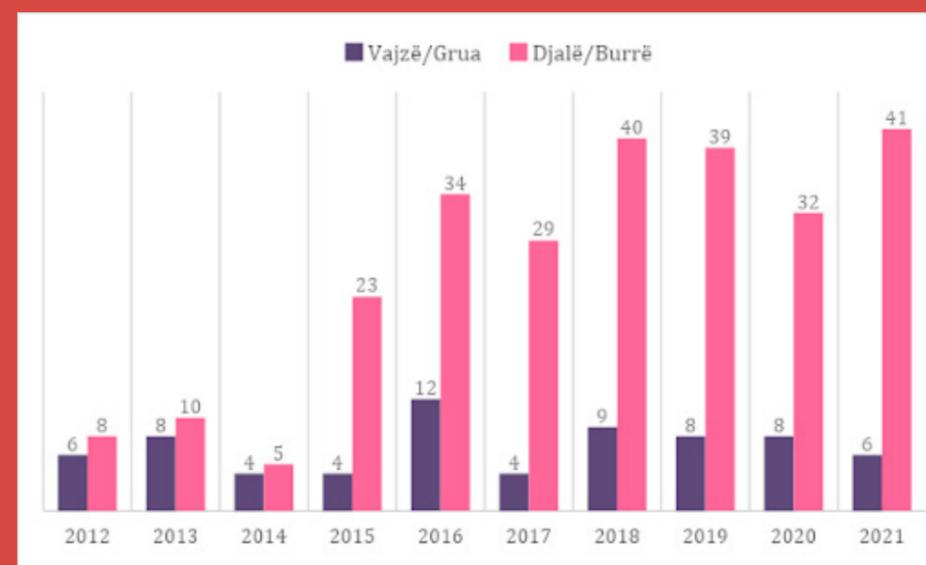
Strengthening and providing opportunities for adult persons with autism is pressingly important in order for them to be able to express their skills and abilities, be that a job placement that is related to their stereotypes, such as: sorting out books in libraries, information technology companies, environment maintenance, where they could immaculately carry out their routine activities.

# ANAK'S ENGAGEMENT

Between 2012 and 2021, ANAK has provided professional therapeutic services for persons with autism and their families. During ten (10) years, there have been 310 persons with autism as direct beneficiaries of ANAK. Graphics below provide a division of beneficiaries in years and gender.



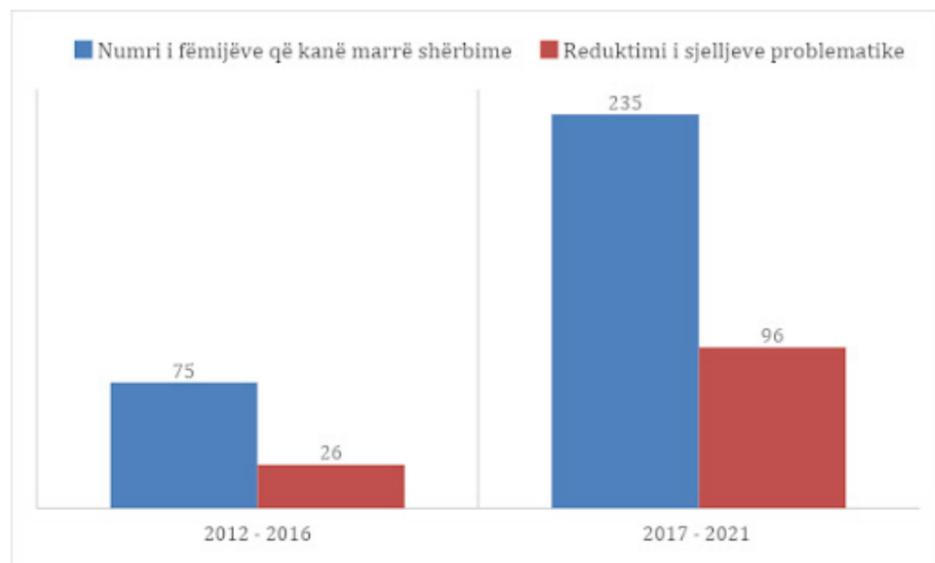
GRAPHIC 1: NUMBER OF CHILDREN WITH AUTISM, DIRECT BENEFICIARIES DIVIDED THROUGHOUT TEN (10) YEARS.



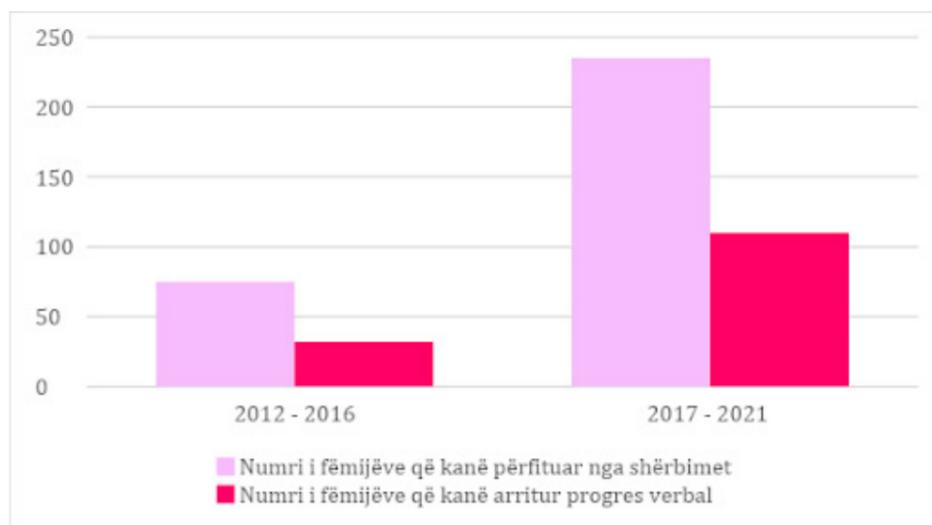
GRAPH 2: NUMBER OF CHILDREN WITH AUTISM, DIRECT BENEFICIARIES THROUGHOUT TEN (10) YEARS, DIVIDED IN GENDER.

## Tangible results

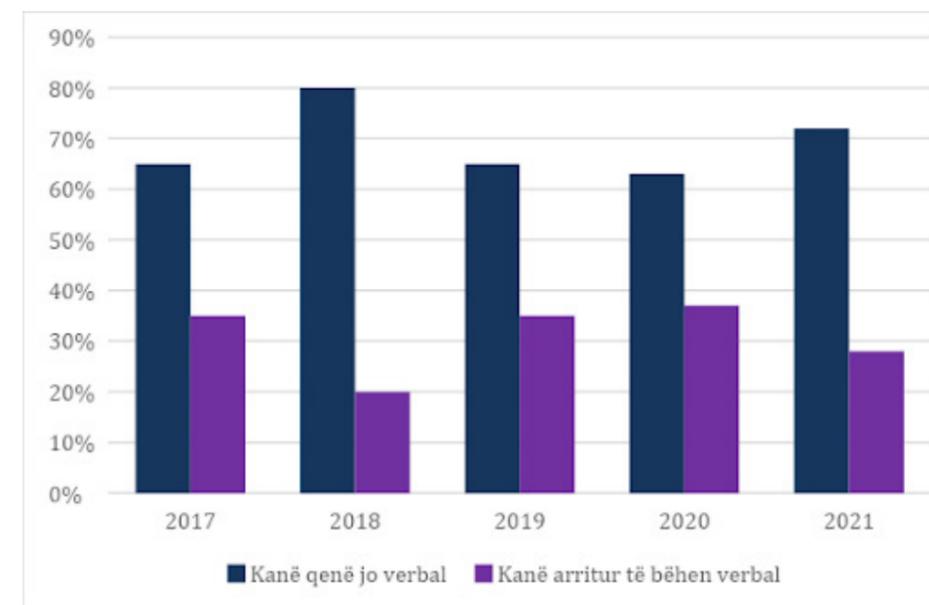
During ten (10) years, out of 310 children with autism who benefited from qualitative individual services provided by ANAK, 142, or 46% of them, have reduced problematic behaviors and have managed to achieve progress in their verbal development. The number of children with autism who reduced problematic behaviors throughout the years are described in graphs below.



GRAPH 3: NUMBER OF CHILDREN WHO BENEFITED FROM ANAK SERVICES AND WHO HAVE REDUCED PROBLEMATIC BEHAVIORS

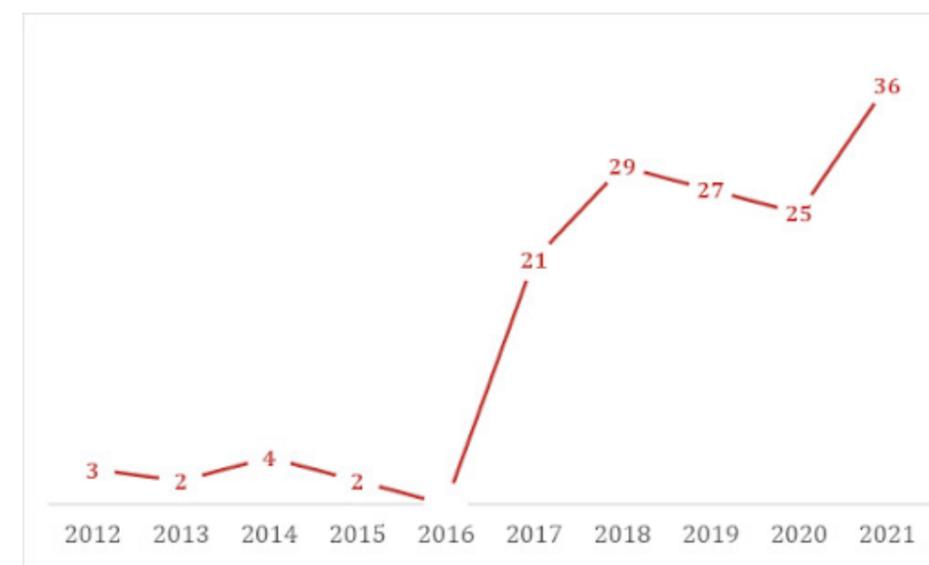


GRAPH 4: NUMBER OF CHILDREN WHO HAVE BENEFITED FROM ANAK SERVICES AND VERBAL PROGRESS HAS BEEN ACHIEVED



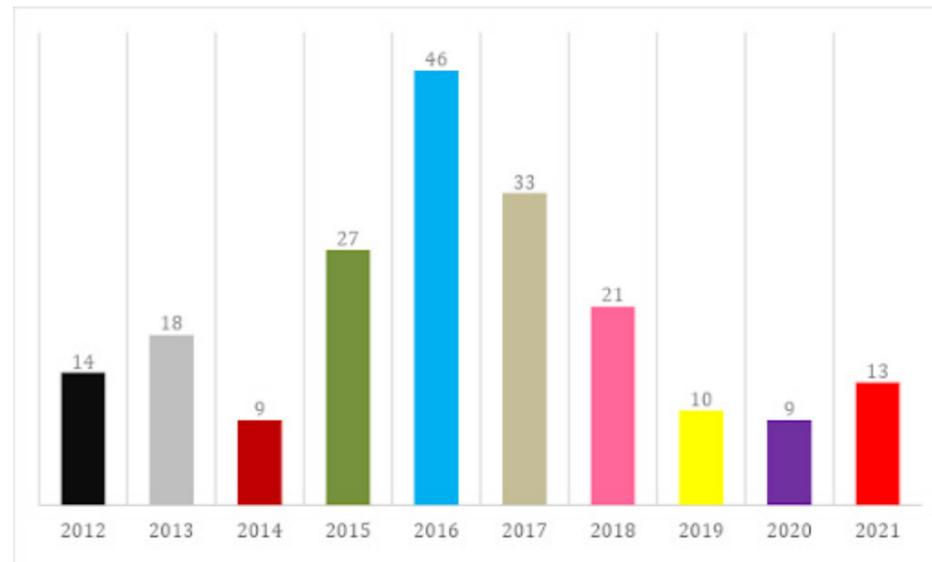
GRAPH 5: PROGRESS OF CHILDREN IN AREA OF COMMUNICATION FROM NON-VERBAL TO DEVELOPMENT OF VERBAL COMMUNICATION

During ten (10) years, out of 310 children with autism who benefited from qualitative individual services provided by ANAK, 149, or 48% of them have been integrated in kindergartens and schools within the regular education system. The graph below displays the number of children with autism who have been integrated in kindergartens and schools, divided in years.



GRAPH 6: NUMBER OF CHILDREN WITH AUTISM WHO HAVE BEEN INTEGRATED IN KINDERGARTENS AND SCHOOLS

During ten (10) years, ANAK has done over 600 assessments of children with autism in ten areas of their development



GRAPH 7: NUMBER OF ASSESSMENTS DIVIDED IN YEARS

During ten (10) years, ANAK has drafted over 280 individual working plans for 280 children with autism, with the focus on improving problematic behaviors, as well as has determined clear objectives for each area of development of receptive and expressive communication, social adaptation, general skills, including impulse self-control, area of motor function etc.

During ten (10) years, ANAK has managed to organize and hold over 600 trainings with different family members of children with autism or children with other similar challenges.

During ten (10) years, ANAK has trained over 800 students of the department of psychology, speech therapy, ergotherapy and education.

During ten (10) years, ANAK has, on voluntary basis, trained and offered consultations for over 89 assistants of children with autism on appropriate approaches and necessary interventions, depending on individual challenges of children during the process of integration in the regular education system.

During ten (10) years, ANAK has had an impact in the direct education and capacity

building of over 1,300 professionals of various fields which relate to autism.

During ten (10) years, ANAK has provided basic trainings on autism, early signs, necessary services and referral procedure, reaching thus 250 healthcare workers in twelve (12) Centers for Family Medicine in seven (7) regions of Kosovo.

During ten (10) years, ANAK has managed to support 52 kindergartens from different regions of Kosovo, including individual consultations for teachers, educators, or through individual assistants of children during the integration process.

## Specific Services and Activities of ANAK

### THERAPEUTIC INTERVENTIONS

Daily direct professional therapeutic services for children with autism and their families provided by ANAK include the following: psychological assessment; drafting of detailed individual plan; training of parents on implementing objectives and specific intervention methods; individual therapeutic sessions; and systematic parent consultations.



ANAK continuously carries out assessments of new cases and drafts individual work plans with a focus on improving problematic behavior, as well as determining clear objectives for each of the developmental fields of receptive and expressive communication, social adaptation, general skills, including impulse self-control, motor function etc.

## PROCESS OF THERAPEUTIC EFFECTS

### Communication development of children at ANAK

Intervention in the field of understanding and expression during the development of communication in certain children where there is a noticeable verbal capacity, is done with emphasized vigilance by therapists who condition and stimulate children to express certain needs in words. During such specific cases in challenging communication development, and following individual analysis of those children, therapists apply strict methods of physically blocking such possible rewards until the child can verbally express his/her need in words. Thus gradually, while these children manage to easily repeat other and different words, they fulfill the memorization of enthusiastic stories throughout the years at ANAK, which serve as inspiring models towards further development in other developmental fields for those children, as well as for future cases which are referred for intervention needs.

### Reducing problematic behavior in children at ANAK

Improvements in resistant behavior in children with autism, as well as in children with neurotypical development, create a space for further development of different and authentic potentials of children, skills which might have been unexplored as yet, while, on the other hand, they were reinforced by the surrounding, through their submission towards children's resistance. The professionalism of ANAK's therapists consists in blocking potential rewards when the child continues to resist when engaged in persistent challenging against resistant behavior by children, who refuse to receive instructions from others, resistance which may last for hours and hours.

ANAK has frequently had cases of children crying for hours, following their reception of direct therapeutic services. After analysis of specific behavior, consideration of situations and linking reinforcements in that particular child, it becomes clear whether cases of children crying might be as a function to fulfill his/her demands, to get attention of others, to avoid tasks/instructions from others or for internal sensory reasons. Following appropriate individual intervention, children almost entirely cease crying. Fending off a child from crying continuously contributes to the development of an interpersonal harmony with other family members or society involved, while at the same time, makes possible for stable conditions for professional focus of parents and

facilitating the approach by school personnel in fending off stigmatization by school peers towards the child in question, as well as can create opportunities for an easier inclusiveness and acceptance by the community.

Therapists' approach methods towards children are shared also with parents of children, who are recommended to continue the same approach at home and other environments as well. Treating children with the same methodological approach is essential for the child to generalize the meaning of cause-consequence, where avoidance of responsibilities or instructions results in blocking rewards, which in turn motivates them in receiving those instructions in the future, since following every cooperation, they have always received desired rewards.

Throughout the years in ANAK, these approaches have made it possible to break the resistance in around 90% of cases, who have benefited from direct daily service, thus significantly reducing harmful behaviors which, following interventions, such behavior remains with a 'non-efficient' function. The progress of change increases and accelerates particularly when families of children continue with same intervention approaches at home or other environments. All individualized and detailed recommendations are provided to the parent/custodian for each child, after ANAK therapists have analyzed and assessed the use of such specific

techniques for special behavior preliminarily.

## INTEGRATION OF CHILDREN WITH AUTISM IN EDUCATION SYSTEM

ANAK has systematically played the role of a connecting bridge between kindergartens and schools, working preliminarily in reducing resistant behavior in children through individual intervention, by generalizing those adapted behavior in different places and with different people, so that they are more cooperative and receive instructions for integration. But, during the practical process of integration, ANAK has continuously faced challenges of an unorganized system in appropriate social services.

In order to effectively support the integration process of children with autism in kindergartens and schools, ANAK has contributed in increasing human resources, exerting an impact thus in increasing the number of individual consultations and specific recommendations for each child. ANAK has constantly provided support to individual assistants and teachers with specific suggestions for each child, as well as supporting their parents through different challenges of the integration process.

ANAK has, on voluntary basis, consulted and trained around 89 assistants for children with autism for appropriate approaches and for necessary

interventions, depending on individual challenges of children during the integration process in the regular education system. Furthermore, when assistants have reported on challenging behavior for specific children, ANAK therapists, alongside objectives determined by the individual plan of that child, have focused on displacement of intervention for that behavior, giving assistants concrete intervention recommendations.

On the other hand, ANAK has systematically advocated for the realization and support of rights of children with autism in the education system.

## RECREATIONAL AND EDUCATIONAL ACTIVITIES

### Adaptation to learning in other environments

Throughout therapeutic sessions at ANAK, adaptation to learning in different environments has been part of therapy. One of the preferred places for learning has been the City Park, courtyard of the organization and participation in Olympic games organized for children. Out in nature, children were able to learn individual and group work, parallel walking, recreation in the play corner, waiting in line and recognizing social norms on protecting the environment.

As part of activities outside of



therapeutic sessions, children receiving care in the organization have participated in different visits, such as 'Utalaya Foundation', whereby through explorative activities in nature and at the forest of bears, they were able to generalize skills learned during therapy in pleasant natural environments.

Further on, in cooperation with the National Library of Kosovo, we organized the activity "Library in the Square", in order to make it possible for children with



autism, who have gifts in meticulous rendering of objects/books, to showcase their skills. This practice serves as a precursor towards potential employment of these persons as future librarians.



A few children from ANAK participated in activities of “Tokyo Olympic Festival 2020”, organized by Kosovo Olympic Committee in Prishtina.



## PARTICIPATION IN EXHIBITIONS

**Exhibition “Embrace Me Kosovo”**, by Dutch photographer Karin Brongers, had a focus on empowering persons with impaired abilities, for a more inclusive and equal society.

**Exhibition “Communication through Art”**, organized by HB workshops contributed financially, by donating the revenues collected from sales of paintings displayed in this exhibition.

### “Evidence Based Future V: Autism”

ANAK and the Center for Psycho-Social and Medical Research (QHPSM), as part of activities on raising awareness about autism, held the event “Evidence-Based Future V: Autism”. The purpose of this event was to present scientific research, which provides the need analysis, which could serve as a basis for building efficient intervention in the field of autism.



In the fifth event of this kind held, a presentation of results of four (4) sets of research carried out in Kosovo was presented which, in comparison to previous times, a special emphasis was placed on presentation of research on Autism and a round table discussion on this topic with several local professionals and policymakers.

### Stand up, Dance, Walk, Scream or Sing!

In 2019, ANAK together with CINEPLEX organized a film day for children in the autism specter and their parents, as part of awareness on autism month. The film was shown in a sensory-friendly environment. This means that during the screening of the film, the environment was fully adjusted in light and sound, in order to remove all possible stimulants, whereas children were free to move around, eat and drink, scream, sing and exit the screening room as many times as they wished. This activity was a very good opportunity of social support and entertainment, but at the same time, it went a step further in developing social skills of children and in supporting the idea that children in the autism specter can enjoy an ordinary day in the cinema.

Such initiatives have an impact in the lives of children and their families and they must be part of cinemas and other cultural platforms, having in mind the aim of creating an accepting and appropriate environment for persons in the autism specter and their families.



## TRAININGS AND DISCUSSIONS

### Discussions

ANAK has continuously developed over 150 discussions with relevant professionals related to the nature of autism, workshops with relevant institutions, and has participated in conferences and professional trainings, with the aim of increasing awareness on autism, measuring possible needs and defining, as practically as possible, recommendations towards strategic institutional solutions. Some of the activities organized by ANAK are as follow:

- **Round table discussion** – Challenges of integration in community”, which focused on highlighting practical difficulties that persons with autism, as well as those with special needs, face throughout inclusiveness.



### Trainings

- **Individual training of children’s families:** Through constant consultations and participation of parents in therapeutic sessions, ANAK has also contributed towards emotional support of parents of children with autism, as well as supported them in utilizing the same methods analyzed to be specifically appropriate for their children at home.
- **Training of Students** Since its establishment, ANAK has had a close cooperation with the Psychology Department of University of Prishtina, and has continued to provide thousands



of practical work hours for students of this department.

- **Training of health workers** Initiatives of ANAK to cooperate with relevant institutions on systematic basis has had a positive impact in a better functioning of the reference chain of cases throughout 2021. In order to increase early identification of cases suspected of autism, ANAK has held basic trainings on: autism, early signs, appropriate services and referral procedure. These trainings have had a significant impact in raising awareness on early detection of children with autism, resulting thus in an increase of referred cases to ANAK by different family centers in Kosovo. Furthermore, some health professionals have referred cases to ANAK, following a review of electronic materials from trainings, coming across suspected cases of autism during their daily ordinary work.



- **Training of social workers** ANAK has held trainings with Centers for Social Work in seven regions of Kosovo, including social workers from: Prishtina, Gjilan, Fushë Kosova, Podujeva, Shtime, Ferizaj, Lipjan, Drenas, Prizren, Gjakova, Suhareka, Mamusha, Dragash, Istog, Klina and Peja. Through these trainings, ANAK has managed to contribute in raising awareness of social workers on autism, autism challenges in the community, role of social workers when dealing with autism in their families, different solutions related to this issue.



Furthermore, ANAK has managed to inform social workers on methods and has provided recommendations of approaches in relation to problematic child behavior, as well as raising awareness on referral of cases with autism and necessary services.

- **Training on adolescence challenges in children with autism**

ANAK has, through this training, managed to bolster awareness of 70 participants, who were parents of children with autism, psychologists, speech therapists, assistants to children with autism in kindergartens and schools, regarding challenges of adolescence in persons with autism, sleep and feeding difficulties that persons with autism go through in childhood, as well as practical intervention methods on understanding and overcoming these challenging situations.



- **Training of staff and parents**

The training focused on “Sexuality and Relationships in Persons with Autism” and “Impact of Stress and Anxiety in Problematic Behaviors in Children with Autism” has contributed in capacity building in ANAK staff and parents of children who receive services in ANAK, regarding dealing with challenges of this nature, as well as identifying methods and possible intervention steps with practical ideas, which were displayed with pictures.



- **Special Education Training**

ANAK’s professional staff has been trained through Special Education Trainings in partnership with TİKA. Areas of trainings have included: education of persons with special needs; learning-based skill development; determination of intended behavior and education specification; development of language skills and speaking in persons with decline; syndrome and autism; behavioral challenges and methods of overcoming; action table; independence, selection and growth of friendship; interaction; sexual development and education; and theory of mind.



- **Practical work and Volunteer work**

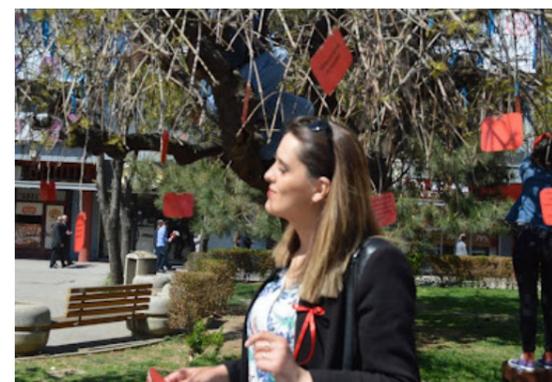
ANAK, throughout the years, has provided around 10 thousand practical hours of work for students of disciplines of Psychology, Speech Therapy, Ergotherapy and Education. This practical work has revealed persons who possess capacities, such as: understanding the essence and logic of behavior therapy techniques, they have reflected patience and unconditional volunteer work, have displayed curiosity through specific questions etc. and they have become part of ANAK for a certain period of time.

In the last year, ANAK has created a new qualitative system of conducting practical hours with a limited number of interns. The method of online training was initially

launched as an adaptation to protective measures against Covid-19 and displacement of student practical hours with separate training modules on the following topics: “Autism and treatment”, “Intervention methods”, “Applied Behavior Analysis”, “Volunteer work at ANAK”, “Assessment of children with autism”, “Drafting of individual plans”, “Entry of data in E-data system”. Following every lecture by mentors, interns had tasks based on topics covered by trainings, then they were assessed and provided feedback on improvements or suggestions. This was done in order for students to benefit from professional skills in writing and reporting, before beginning work with direct case observations. On case observations, interns submit case reports (only for internal use and issue of professional supervision by ANAK). The persons included have also contributed in other activities organized by ANAK.

- **Autism awareness-month campaigns**

Having in mind continuous challenges ANAK faces, children with autism and their families suffer from erroneous perceptions on autism, which has historically made it more difficult and continues to block the development of social service provision for persons with autism and their families. Therefore, since its establishment, ANAK has developed and carried out awareness campaigns, which have aimed at sharing knowledge about autism, needs of persons with autism and their families, as well as the provision of necessary services which must be provided to persons with autism, by always highlighting their extraordinary skills and potential to integrate in society.

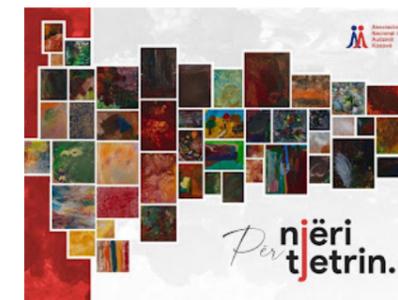


Below is a list of campaigns that ANAK has organized from 2012 until 2021:

- The campaign **“For one another”** continued advocacy through art and not victimization, promoting thus authentic skills of children with autism, towards establishing essential services.



- The campaign **“For one another”**, which promoted talents of children with autism through the sale of paintings created by them, the amount which has been used to enable the provision of essential services free-of-charge for children with autism who face a more difficult socio-economic situation.



- The campaign **“Contribute for autism”**, served as a calling for persons with autism to be treated equally and justly in Kosovar society based on their skills, needs and their potential. This vision has gone beyond treating persons with autism on equality basis, since, in itself, this has been a discriminating notion when we consider the unique nature of persons with autism, their skills and abilities, their needs and their potential.
- The campaign **“For one another”**, contributed to raising awareness for companies, individuals and organizations on necessary services for children with autism and managed to raise funds to enable essential services for children living on dire economic situations, specifically providing free-of-charge individual sessions for children with autism, who were the most affected by Covid-19.

- On increasing awareness about autism, ANAK organized the activity “**Cycling for Autism**”, whereby, through sports and in an autism-friendly environment, many cyclists, children, parents, volunteers joined the journey to Germia park, as a sign of solidarity and support for the rights of persons with autism.



- ANAK and the Center for Psychosocial and Medical Research (CPRM), as part of efforts in increasing awareness about autism, developed the event “**Evidence Based Future V: Autism**”. The purpose of this even was to present scientific research, which provide the behavior analysis and which can serve as a foundation for building efficient nterventions in the area of autism, as well as a roundtable discussion on this topic with local professionals and policymakers.



- As a mechanism for further increasing awareness of educators and other persons who are directly involved with children with autism, ANAK has undertaken consultations, trainings and free-of-charge lectures regarding practical interventions based on behavior analysis and verbal analysis.
- Abstract paintings of children from ANAK have participated even in the exhibition “**Speak Up Kosovo**” at the American School of Kosova.
- To mark the International Children’s Day, ANAK organized “**Art in Autism**” in the National Library of Kosovo, being the first exhibition in Kosovo with artworks made by

children with autism who are beneficiaries of direct services at ANAK. Being that communication is one of the three fundamental difficulties for persons with autism, through art, they have expressed themselves by replacing verbal communication with the language of colors. The liveliness and positivity reflected in the paintings reflected best the multicolor world of children with autism. The children’s artworks were accompanied with descriptions of children’s features, which added meaning and curiosity to readers in order to analyze paintings more and understand their world.



- Apart from the tradition of decorating the tree with different quotes, ANAK has undertaken activities with lectures for students of particular fields, and the awareness process this year has resulted with more social interest about autism and concrete needs related to it.
- “**Artistic Exhibition of Children with Autism**”, which aimed at promoting artistic skills of children with autism, and at the same time, advocating to relevant institutions in Kosovo in order to further inspire and promote these skills through building necessary professional services for autism.
- Campaign “**I have the right to be different**”, where ANAK organized activities in all Kosovo regions through the distribution of quotes on autism and other decorations with sayings on autism, presenting individual characteristics of persons with autism.
- Having in mind social pressure in putting focus on difficulties rather than skills and potentials, for the month of April (autism awareness month), ANAK organized the awareness campaign “**Autism and Talents**”. Apart from the already-established tradition of decorating the tree with quotes on autism in all regions of Kosovo, this campaign also saw a concert by the musical genius, who is also autistic and blind, Mr. Derek Paravacini. His visit marked a sharp turn in the perception of persons with autism in general, but it especially contributed to increasing the courage and

willingness of parents in understanding and accepting more than ever difficulties and challenges of autism, and at the same time, their willingness to emphasize skills and potentials of their children.



- Awareness campaign in seven (7) regions of Kosovo, which saw volunteers of Psychology students decorating a tree in each region with quotes on autism and unique skills of persons with autism.



- With the support of Rona Nishliut, Genc Salihut, Gipsy Groove and Hamam Jazz Bar, a concert was organized on the international autism day, which aimed at raising awareness on autism through fundraising for the organization through paintings made by ANAK staff itself.
- Through DAM Fest with the motto “**Autism and Music**”, ANAK distributed written information to the audience on autism and their extraordinary skills in music.
- Discussion panel with the Psychology department on the importance of initiating necessary services.

## INSTITUTIONAL COOPERATION

### Psychology Department, University of Prishtina

Since its establishment, ANAK has had close cooperation with the Psychology Department of the University of Prishtina. As a cooperation partner, ANAK provides opportunities for students of Psychology Department to hold practical hours by participating in therapeutic sessions, with the aim of professional advancement in treating persons with autism.



### Institute of Psychology, University of Prishtina and Ministry of Education, Science, Technology and Innovation

ANAK has a well-established cooperation with the Institute of Psychology, University of Prishtina and Ministry of Education, Science, Technology and Innovation, as it plans to organize the process of preparing and drafting structured modules of trainings for the Master level of School Psychologists. This process, apart from drafting materials, will result also in the publication of reports and research with different professional inputs through analysis of different variables in the systematic data, which are entered in the science program E-data at ANAK.

### Centers for Social Work in Kosovo and Department for Social Work in Prishtina University

Throughout ten (10) years of work, ANAK has contributed towards capacity building of social workers who work directly with families of children with autism. During its work, ANAK has observed that social workers face difficulties in treating persons with autism because of lack of psychologists within centers for social work and other elementary conditions. Furthermore, the non-division of categories for managing cases further complicates the referral system and knowledge.

The large number of cases that need treatment under the management of social workers makes it impossible for practical referral solutions and monitoring of difficulties that families face during integration of their children.

On the other hand, through cooperation with the Department for Social Work, the University of Prishtina contributes towards the development of the area of social services through training students of this field, towards a more efficient future development of social services.

### **Department for Social Welfare, Municipality of Prishtina**

The close cooperation with the Department for Social Welfare of Prishtina Municipality has played a powerful role in the proper functioning of ANAK's service. This role consisted in financial support for ANAK for several years in a row, covering essential expenses of the office. Furthermore, we have together evaluated determining steps for subsidizing services for persons with autism and their families in the future, starting with free-of-charge provision of the "Essential Package" for each child with autism in Kosovo and their families.

## **INDIVIDUAL INITIATIVES FOR SUPPORTING ANAK**

### **Mini-Marathon "Run for Autism"**

In 2015, through the initiative and full support of Aferdina Paqarada, we organized the Mini-marathon with the motto "Run for Autism", which not only gave a push forward to existing services in ANAK, but also had a further impact in raising awareness and social perception on autism, exerting influence also in the willingness to support necessary services.



In 2019, the 5 km Mini-marathon "Run As Well" was organized by Aferdida Paqarada and Diellca Kolgeci, with the money dedicated for urgent services for children with autism.

## Support from Sunny Hill Foundation and Dua Lipa

In August 2018, world-famous singer, Dua Lipa, through her foundation “Sunny Hill” contributed to ANAK with the amount of 5,000 Euros, which considerably eased the emergency situation, through the purchase of qualitative pedagogical and recreational tools, with a small library for children inside the center, as well as covered unforeseen financial difficulties in cases when parents’ contribution for their children’s services was not possible.



### Përkrahja nga Sunny Hill Foundation dhe Dua Lipa

Në Gusht të vitit 2018, këngëtarja me famë botërore, Dua Lipa, përmes fondacionit “Sunny Hill”, ka kontribuar në ANAK me shumën prej 5,000 Euro të cilat e kanë lehtësuar dukshëm gjendjen emergjente në qendrën tonë me mjete kualitative pedagogjike dhe rekreative, me librarinë e vogël për fëmijë brenda qendrës, si dhe ka mbuluar vështirësitë e paparashikueshme financiare në rastet kur kontributi prindërvë për shërbimet e fëmijëve të tyre ka qenë i pamundur.

## CHALLENGES THROUGH THE YEARS

Some of the challenges that ANAK has faced during ten (10) years of work are as follow:

- Lack of long-term financial support, which ensures sustainability for the organization; consequently, the provision of quality therapeutic services for children with autism and their families;
- Lack of financial support from different donors in overcoming challenges which the organization faces, especially related for infrastructure and adequate and necessary equipment for treating and providing services for persons with autism;
- Lack of qualitative pedagogical and recreational tools;
- Lack of institutional support in creating adequate infrastructure for treating and supporting children with autism and their families;
- Lack of institutional support in increasing capacities of teachers and educators on autism and proper and effective methods in treating persons with autism;
- Disorganized system in appropriate social services;
- Lack of conditions for treating adolescents with autism;
- Lack of willingness by the side of public and private institutions regarding integration of persons with autism, specifically in creating job positions.

## ANAK IN COMING YEARS

ANAK aims to keep institutions and society in general informed on the authenticity of persons with autism, their unique talents, needs for dignified services, and to advocate on inequality regarding their rights in the face of a lack of proper functioning of political, economic and social systems in Kosovo. The advocacy steps of ANAK are focused on reviewing and covering the following fields:

### COMPREHENSIVE LAW

Part of ANAK's advocacy program is also engaging in drafting of the "Draft Law and Final Report for the Draft Law on Assessment, Recognition of Status, Benefits and Services for Persons with Impaired Abilities", which will contribute further more towards a financial stability from state resources for persons with autism and especially their families. The new law for social services and families aims to address the needs for multidisciplinary teams in relevant educational institutions, and especially for placing psychologists in centers for social work.

### PROVISION OF FREE-OF-CHARGE ESSENTIAL PACKAGE

ANAK is working strongly towards making it possible for all children with socio-economic challenges in Kosovo to receive free-of-charge "Essential Package", which includes" individual evaluation (for each child with autism or suspected of being autistic), drafting individual working plans, training of each family specifically in intervention procedures, as well as regular weekly therapeutic sessions with children, accompanied with regular consultations with their families. In achieving this social model, the aim is to have subsidies of services by public institutions, as well as sustainable and long-term sponsoring by companies, banks or various businesses. With a stable functioning of the essential package, ANAK will continue advocating by presenting this system to the Government of Kosovo and competent institutions, and will draft plans and long-term strategies towards realizing direct services for each child in Kosovo without discrimination.

### DAY CARE FOR PERSONS WITH AUTISM AGED OVER 18

ANAK will advocate for the establishment of a day stay for persons with autism who are of over 18 years of age. The day stay is proposed to provide activities which stimulate their potential towards independence and involvement in practical things, which may contribute to opportunities for employment, depending on skills or abilities and stereotypes/repetitive behavior.

### ENABLING FREE-OF-CHARGE INDIVIDUAL ASSISTANTS

Through financial support from various donors, ANAK aims to cover the payment for individual assistants of children with autism who are going through the integration process in kindergartens and schools and who have challenges of socio-economic nature.

### SYSTEMATIC MONITORING OF SUPPORTING ASSISTANTS

ANAK will work towards establishing a professional and ethics commission, which will have a supervisory role for assistants working with children within the regular education system in Kosovo, and to review progress/challenges of children with autism throughout the entire process.

### ENSURING A MULTIDISCIPLINARY TEAM THROUGHOUT THE DIAGNOSTICS PROCESS THROUGH HEALTH INSURANCE

Based on challenges pointed out by parents, it is necessary, in cases of suspicions by family members regarding the development of their child, to enable the establishment of a diagnostics team, consisting of a child psychiatrist and pediatrician in kindergartens and schools.

### RAISING AWARENESS AND ADVOCACY CAMPAIGNS

ANAK has and continuously advocates for Centers for Social Work wot have separate categories, which would manage cases of Kosovo citizens being admitted, including persons with autism. This is crucial for the system of knowledge and adequate and specific referrals, as well as for proper access to social services and for the practical handling of difficulties that families of persons with autism face.

### DEVELOPMENT OF METHODOLOGIES AND PROFESSIONAL MODULES

ANAK plans to focus its efforts in developing methodologies and advanced professional modules, which at the same time would fill in a serious gap in necessary literature and professional intervention presentations in Albanian.

ANAK aims to work towards tangible integration of children with autism in the regular education system, through students of psychology and pedagogy, in which case they replace the obligation for practical work in an official commitment to directly assist children with autism. This objective will enable a concrete change through" individual integration of children, where the parent would not be held to pay for an assistant for the child; committed students would benefit from officially recognized work experience; and the Municipality would carry through its obligation for quality education and inclusiveness.

## CREATING EMPLOYMENT OPPORTUNITIES

ANAK will create opportunities for persons with autism to benefit from provision of programs for development of crafts, artistic expression or development of different capacities. This approach creates the possibility for preparing persons with autism to be more competitive in the labor market. Additionally, ANAK is in the process of raising awareness of companies and Kosovo institutions, regarding rare skills that persons with autism may have and employment opportunities for them. Currently, the Kosovo National Library has been identified, as well as a company dealing mainly with information technology development.

ANAK aims to achieve this objective by 2023 by cooperating with institutions of developed countries and local institutions/companies, different businesses etc.

## FREE-OF-CHARGE ONLINE SUPPORT

By 2023, ANAK aims to establish a network of a Support Phone Line for children, schools, kindergartens, and the wider community, who will be able to access basic information on autism, necessary services, or other information related to rights of persons with autism.

# CURRENT ANAK DONORS

## Existing projects

**Department of Social Welfare, Municipality of Prishtina**, which, during 2019-2022 is supporting ANAK space with expenses for basic municipal expenses, a space which is used to provide direct therapeutic services for children with autism, psycho-social services and organizing other professional activities.

**Ministry of Education, Science, Technology and Innovation** evaluated ANAK's project in 2021 "Functional and qualitative integration of children with autism and comprehensive awareness", awarding financial support for its implementation.

**Ministry of Finance, Labor and Transfers** in 2022 evaluated ANAK's project "Therapeutic service for children with autism who face socio-economic challenges and wellbeing of parents" awarding financial support for its implementation.

## Other contributors throughout the years

- **Solidar Suisse** has been an inseparable partner of ANAK since 2012, continuously supporting ANAK with professional consultations as well as financially. Together with Solidar Suisse, ANAK has undertaken powerful efforts in advocating for the inclusion of the essential package of necessary services in plans for health insurance.
- **Embassy of the Netherlands:** providing direct support in seven (7) first months of the functionalization of the center in the implementation of the project "Bridging integration and independence of persons with autism" and ensuring working environments in the first fourteen (14) months;
- **KFOS:** by providing direct support in the first seven (7) months of service through co-financing of the project "Bridging integration and independence for persons with autisms";
- **Shkelzen Maliqi:** by offering his office for use in carrying out direct services for a period of time;

- **Parents of children with autism:** by contributing in regular monthly basis since 2014 to provide for therapeutic services for children with autism;
- **Volunteerism of ANAK staff and students of Psychology Department:** by providing their contribution in carrying out different activities, especially during awareness campaigns;
- **Pro Credit Bank:** by providing support through a grant which was used to purchase pedagogical tools;
- **Hamam Jazz Bar:** by offering its space to organize different events for autism, with a special emphasis on fundraising events;
- **Ministry of Labor and Social Welfare:** by providing support since 2014 in covering rent expenses for the work environment and purchase of pedagogical tools;
- **Department for Health and Social Welfare, Municipality of Prishtina:** by providing support in assisting families in need and covering some pedagogical expenses;
- **Department for Culture, Municipality of Prishtina:** by supporting the awareness campaign in lighting the municipal building and NEW BORN monument in blue, and has also contributed in bringing the musical genius Derek Paravacini in 2015;
- **British Council:** by providing support in bringing the musical genius with autism Derek Paravacini, in raising awareness on abilities of persons with autism;
- **Ministry of Culture, Youth and Sports:** by co-contributing in bringing the musical genius Derek Paravacini and organizing the swimming activity for children;
- **Hotel Emerald:** by providing space for the concert by Derek Paravacini and providing food and drinks for participants;
- **Valdete Deva:** by creating essential and recreational furniture for the center, especially at the beginning of ANAK's work;
- **Aferdita Paqarada:** by providing contribution in offering financial support for social cases, collected through the marathon "Run for autism";
- **Fikrie Gagica Ukelli – Ceka:** by donating 100 books with recipes, which were sold to cover necessary expenses at ANAK;
- **Ricoh:** by printing color pictures, which were used to stimulate communication in children;
- **Meridian:** by donating drinks for a campaign and by contributing in organizing a fundraising event;
- **AAB Faculty:** by providing support in a swimming activity;

- **Lighting - Egzoni and EZ Vision:** by contributing in lighting public spaces on the occasion of April 2nd, the international autism day.
- **Turkish Agency for Cooperation and Coordination - TIKA:** by contributing in furnishing the center with a full inventory;
- **Dukagjini Library:** by allocating 10% of profits from sales of books in supporting emergency services at ANAK.

