

"Politika" in partnership with UNICEF dedicates this page to the findings from the meeting "Living with Autism" organized by UNICEF, Association for Child and Adolescent Psychiatry and Allied Professions of Serbia, Serbian Society of Autism, Ministry of Health, Ministry of Education and Autism Speaks

## HOW TO PROVIDE HIGH QUALITY LIFE TO PEOPLE WITH AUTISM

### Timely identification of the disorder is the most important



Autism is a spectrum of neurodevelopmental disorders characterized by problems with communication, social interactions and repetition of certain patterns of behaviour. The first signs of autism can occur at the earliest age, says Dr Maria Luisa Scattoni, coordinator of the Italian Network for Early Diagnosis of Autism Spectrum Disorders and senior researcher at the Institute Superiore di Sanita in Rome.

"The most important thing is to detect disorders while the child's brain is developing, because that's when we can teach certain patterns of behaviour to the child and direct them in the right way", Dr Scattoni explains for "Politika".

Disorders related to autism most often occur between the months 14 and 19 of a baby's life: those are the lack of initiative, speech development delays, and problems with motoric skills... It is known that genetics affect the occurrence of autism, but in order for this disorder to actually occur, several risk factors must "intersect" – genetics, environmental pollution, especially with pesticides, elderly primgravidae, less than 12 months between two pregnancies, multiplied pregnancies,

infection in the pregnant woman... Maria Luisa Scattoni mentions that each of these risks on their own does not pose a danger for occurrence of autism, but that in certain circumstances if several risk factors are joined, they can together be the causes of autism.

"One percent of the population has a gene mutation that may be linked to disorders related to autism", says Dr Scattoni.  
*D.I.*

### Attending schools regularly

Children with autism need to be provided with good health care and social care, but also with the high quality education their peers also get. Most of the children with autism in Great Britain acquire knowledge in regular elementary schools, 73 percent of them, while the remaining 27 percent attend special education schools, explains Sarah Parsons, professor at the University of Southampton in Great Britain. According to studies conducted in Great Britain, peers of people with autism have great influence on their education, but according to the professor's assessment, it is important to implement the rule that the approach that is valid for one child with autism is not valid for all of them.

## The greatest burden is on the family

*Diagnosing is late, there is a lack of day care institutions, adequate health care and social protection...*



*UNICEF Representative Michel Saint-Lot and Andy Shih from Autism Speaks*

In the United States of America one in 68 children has autism, in Great Britain this number is one in a hundred, and in Italy one in 250 children is autistic. However, nobody knows how many people with autism live in Serbia: there is no registry, which additionally aggravates the life of people with autism because the system often does not recognize them, so they cannot get help, social support, adequate health care...

Although, according to some data, there are several thousand people living with autism in our country, it is estimated that the number is far greater. Only in Nis, as it was heard at the international symposium "Living with Autism from the Perspective of Patients, Parents and Professionals" recently held in this city, according to the latest information there are around 500 people with disorders associated with autism.

The first reliable data, as announced by the Minister of Health Zlatibor Loncar when opening this meeting, will begin to be collected at the end of 2017, because there is ongoing preparation of the registry of children with disabilities which is recommended by the National Programme for the Development of Children in Early Childhood. This data will contribute to better planning of services for children and their families within all levels of health care.

This is only the first step in what needs to be done to provide high quality of life for people with autism, but also for their families, who

bear the greatest burden: in Serbia we are faced with late identification of symptoms of disorders associated with autism and delay in making the diagnosis. In addition, in our country there are not enough centres for providing early interventions, there is a lack of experts in this field, there are also problems with the capacities for day care, formal education...

"It is not enough just to determine the number of people with autism, but good assessments must be made and every child must be provided with what they need. It is necessary to ensure a better position of children with autism and other developmental disorders and their families", says Michel Saint-Lot, UNICEF Representative in Serbia.

He points out that we must also resolve problems concerning the capacities necessary for day care and other types of accommodation for people with autism, and that better inclusive education is also needed.

*The first data on the number of children with autism in Serbia will arrive at the end of 2017 when the registry of children with disabilities is completed*

*Dejana Ivanovic*

### **Shih: No link between autism and vaccines**

In recent years there has been a drastic increase in diagnosing of people with autism, explains Andy Shih from the international organization "Autism Speaks". There are several reasons for that, this expert explains for our newspaper: paediatricians, but other professionals too, better recognize the symptoms of autism, parents are more informed about this issue and recognize the signs that link to autism, methods of diagnosis have been improved, but also there is more and more air pollution that people are exposed to and the use of pesticides keeps increasing.

"The Centre for Disease Control in the US records new cases each year, while the US government publishes the latest data on the number of people with autism every three years", Mr Shih explains.

Many people associate autism with vaccination of children against serious infectious diseases at the early age. Mr Shih, however, asserts for our newspaper that this link has never been proven.

"We have checked these stories, both together with the state and also on our own as an association we have spent millions of dollars exploring the existence of any link between vaccination of children and the occurrence of autism. Despite the detailed studies, such a connection has not been established", this expert says.

D. I.

### Adults must not become invisible

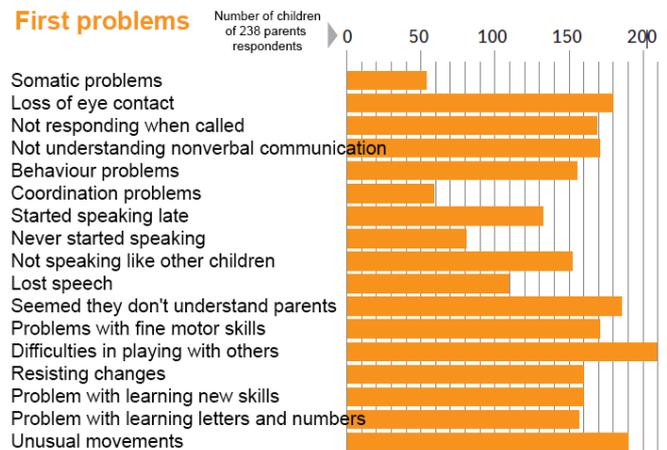
Vesna Petrovic is the president of the Serbian Society of Autism, which was founded by mothers 40 years ago, and all its members are searching for systemic solutions that would make the lives of people with autism and their families easier. As a mother of a son who is thirty-eight years old, she knows very well what it is like to fight with the state such as autism in Serbia. From her personal experience and insights from parents and children she meets both in Serbia and around the world, she emphasizes that the most important areas are diagnosis and early intervention, right to education and work, health care and social care and assistance to families. Adults with autism must not become invisible. Because for them, as they grow up, there is no further education, no socialization, they simply disappear.

JST

### Diagnosis is most often made at the age of four

Autism is more common among boys than girls and usually in the ratio of about four to one. The first symptoms in children at an early age are mainly observed in play, it seems to parents that the children don't understand them, that they behave strangely, do not respond when called, resist changes, have problems with learning new skills... A large percentage of children do not speak or use only individual words of phrases made up of two or three words, and a smaller percent of them use complex sentences. Mothers are usually the first to express concern for the

child, because they are the ones spending the most time with the child.



Parents had the opportunity to list several different problems. The most frequent first signs of problems they faced among their children were difficulties in communicating with other children, presence of unusual movements or actions, lack of understanding, loss of eye contact, etc... (not responding when called, not understanding any form of communication, behaviour problems) Questionnaire Amy Daniels and SEAN

These are only some of the results obtained from 238 respondents who answered questions about the needs of parents of children with autism. The authors of the questionnaire which was administered in Serbia from October last year until the end of January of this year are Amy Daniels and the organization SEAN (Southeast Europe Autism Network) and the results were presented by docent Dr Milica Pejovic Milovancevic, child psychiatrist.

The responses show that the largest number of children was diagnosed at the age of 3.3, by a child psychiatrist or a team of professionals, a neurologist... Parents usually turn to child psychiatrists and psychologists and child neurologists for medical care.

We should not forget that, statistically speaking, there is one medical specialist for every 47,497 children and adolescents in Serbia. The total number of neuropsychiatrists, psychiatrists and child psychiatrists working with children and young people in psychiatric institutions in Serbia and within the regional health care centres, primary health care centres and in private practices is 46 doctors. The total of 27 child psychiatrists have completed their specialisation by 2015. In addition to

Belgrade, Nis and Novi Sad, the following cities and towns have one specialist of child psychiatry each: Sremska Mitrovica, Sabac, Kraljevo, Krusevac, Bor, Cacak, Jagodina, Cuprija and Vrsac. At the moment, there are 20 doctors attending specialisation.

Parents usually get information on the Internet, on the forums and websites, and not from professionals, which can be an additional problem, a large number of them, around 32 percent out of 238 respondents to the questionnaire, feel helpless because they have a child with autism, and around 30 percent of them believe they are discriminated against.  
*Julijana Simic Tensic*

### **Establishing rules of conduct**

The education system can provide support services that are neither complicated nor demanding, points out Ljiljana Simic, associate for inclusive education at the Ministry of Education, talking about school and social programmes for support to children and parents. This means that the child should be allowed to become completely familiar with the new space, to carry out some of their ritual actions, and to return to the activity they started. It is important to establish rules of conduct, the sequence and schedule of activities and to stick to it, to announce every change when it departs from the usual, to give them simple and short tasks, and not to interrupt them in the started activity, and if it is really necessary, then prompt them to quickly finish it.

In one school a boy with autism could not sit for 45 minutes in the class, he would get up and walk around the classroom. Of course, this also disturbed the work of other students. The teacher solved the problem in the following way: she stuck duct tape on the floor and told him: "You can walk, but only up to this line". When you make a deal with these children, they consistently comply until a new rule is introduced. When later she wanted to contribute to his self-regulation, the teacher made a small cardboard traffic light. During the class, not disturbing anyone, instead of asking whether he may get up, the boy would raise a green cardboard man. The teacher would answer by showing him either a green

or red man, depending on the situation. This example shows that even when the child doesn't speak, it doesn't mean he or she cannot communicate.

*J. S. T.*

### **Team of experts and parents as help for the child**

Early identification of children with autism is the key to their progress and more favourable outcomes. In this case it is possible to provide timely support and educate families, and this is the way towards better language skills, social relations... Dr Miodrag Stankovic, child psychiatrist, points out that screening exists in some places but that it doesn't exist on the systematic level in Serbia, and it is more than necessary. In our country there is no appropriate education centre, there are no trainers who would work with children and parents, there are no specialized guides, but there is interest for connecting professionals at all levels and this is extremely important for both children and adults with autism, Dr Stankovic notes. Psychiatrist Dr Nenad Rudic pointed out that even when the diagnosis is made, there is no specific cure. The treatment is usually a very intensive undertaking that involves the family of the child and a whole team of experts. Everyone must take part in the interventions: the health care, social protection and education systems.

*J. S. T.*