

RESEARCH VACCINES AND AUTISM

Life with autism: (In)visible little people

Among children with autistic spectrum disorders in Serbia, 79 percent of them are male, and 21 percent female; the concern for the child is first expressed by parents themselves, and not by a paediatrician; the first three most prominent characteristics, based on which they noticed the problem are – difficulties with other children, abnormal movements and not understanding parents

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It is estimated that about one percent of the world population suffers from autism. The incidence of this disorder has been on the rise in the past decade in the western countries and in the USA, where one in 68 people has autism. There is no official data on the number of people with autism in Serbia, which makes their lives, and the lives of their families, who carry the entire burden, significantly more difficult. Science has been having more and more answers to why autism occurs. Some of the negative impacts are exposure to antiepileptic drugs – valproic acid during pregnancy, the age of the mother and father, high levels of air pollution during pregnancy. This connection is subjected to a systematic examination of strict scientific criteria. Genes control this connection.

A more severe illness or infection during pregnancy, including serious reactions to bacterial and viral reactions (some of which may be prevented by vaccines), obesity during pregnancy, premature birth, complications during pregnancy, most probably through synergy with genes – are also some of the adverse factors.

In addition, science has evidence about how to intervene when it comes to

autism: early recognition of developmental delays, early interventions in order to mitigate the delays, inclusion in normal life activities: kindergarten, school, work, as well as an individualized approach for the person and his or her family.

That is why early identification of children with autistic spectrum disorders, as this disease is called in the scientific community, is crucial for their progress and further development, because it makes it possible to intervene on time, to provide adequate support and education to parents and thus reduce family stress. The continuous increase in the number of children with autism, but also a growing awareness of experts, as well as parents, emphasizes the importance of early identification because it determines their future life.

Due to the fact that there are still no answers to many of the questions, parents in Serbia, and also all around the world, are very concerned about the possible connection

More than 2,000 genes are involved in the reasons for formation of autism. There is no one cause of autism, there are many of them and that's why there are different treatments. If we discover the cause, we will know which treatment to use

between vaccines and autism, which has been much debated in previous years and which is what strengthened the anti-vaccination movement the most. But is there really a relevant scientific study, based on facts and hard evidence, which proves that vaccines cause autism? At the



recently held gathering at the Institute for Early Childhood Development of the Columbia University in New York City, participants from 28 countries, among them top experts in the field of neuroscience, early childhood development and brain development, talked in one of the panel discussions about the impact of society and culture on how the child will be brought up. Precisely because of the anti-vaccination lobby that is growing stronger, especially in developing countries, it was pointed out that there is no study that would confirm the link between the famous MMR vaccine and autism. On the other hand, not receiving vaccination, according to the speakers, was creating many more problems for a nation's immunity than it was assumed, which was why some of the countries set the objective – to educate parents, above all mothers, about the importance of vaccination.

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Andy Shih from the world's biggest organization for autism, "Autism Speaks", says for Nedeljnik that a lot of money has been spent in the previous years to examine the link between vaccines and autism – and that no study has confirmed this link

years to examine the link between vaccines and autism – and that no study has confirmed this link. "Governmental and non-governmental agencies and foundations have invested millions of dollars during the previous decade in studies around the world and the connection between vaccines and autism has not been

found. One of the reasons why many parents link autism with immunization is because children are vaccinated between the ages of 18 and 24 months, in the same period when symptoms of autism become much more obvious. Therefore, this connection is often interpreted as a causal relationship. There is a possibility and need for the government and professionals to raise awareness and provide information based on evidence so that parents can be better informed about early childhood development and autism."

Therefore, the best conclusion of everything was maybe given in one sentence by one parent: "Instead of spending so much money on studies examining whether vaccines cause autism, it is better to redirect that money to research for finding the cure for autism."

Andy Shih also explains why the number of people with autism is growing.

"The studies show that the reasons for the dramatic increase in the number of people diagnosed with one of the autistic

spectrum disorders in the past decade are: 1. increased public awareness of autism, 2. more health care professionals who identify and diagnose the disorder, 3. fewer

cases of autism are mistakenly diagnosed as another condition (e.g. mental disability). However, many scientists believe that those reasons do not explain the entire picture, and that it is possible that some external environmental factors also play an important role. We are starting to identify some of these environmental factors. But more research is needed in order to better identify and understand the risks from the environment for autism", Mr Shih says.

Studies show that autism develops more frequently in boys than in girls (one girl for every four boys) and that incidence is higher among boys and is one out of 42 boys.

A recent study published in the Nature magazine shows that there are morphological changes in the brain structure, which are an early indication (in children six to twelve months old) of autism – in other words: long before the second year of life and the MMR vaccine. In the largest-ever study, which was published in the Journal of the American Medical Association, and which analysed health records of 95,727 children, including more than 1,000 children unvaccinated at the age of two and more than 8,000 still unvaccinated at the age of five, the researchers found that the MMR vaccine did not increase the risk of autism. This was even proven for children already considered at risk for autism – 2,000 of them from families that already had a child with autism.

The authors of the study pointed out that "consistent with studies in other populations, we observed no association between MMR vaccination and increased autism risk".

The first signs of autism are noticed most often in the second year of the child's life, but can be seen much earlier, practically from birth, and definitely already at the age of six to twelve months. The parents are the first ones to notice the symptoms, even before

paediatricians. The clinical indicators of a suspected autism spectrum disorder are those (according to Filipek et al., 2000; New York State Department of Health, 2013) when a child does not make eye contact when someone speaks to them, doesn't wave "bye-bye", consistently doesn't respond when called by their name, does not respond to simple verbal orders ("Give!", "Come!", "Sit!", and similar), does not speak the words "mom" and "dad" (with the meanings), doesn't point to body parts when asked (ear, eye, nose), doesn't point to objects with their index finger, and when a child does not look in the direction shown by another person with a finger. The causes of autism are associated with genetics, but lately there have been many new discoveries that also point to the environmental factor.

Maria Luisa Scattoni, from the Italian Network for Early Diagnosis of Autism Spectrum Disorders, explains that only 20 percent of problems with autism spectrum disorders can be explained by genetic mutations, and that some environmental factors are associated with autism, such as pesticides.

"The first two years of life are very important for the development of the disorder, and some of the factors are the age of parents, infection of the mother, low birth weight, chemical impact... But the strongest influence is a genetic disorder. More than 2,000 genes are involved in the reasons for formation of autism. There is no one cause of autism, there are many of them and that's why there are different treatments. If we discover the cause, we will know which treatment to use", Ms Scattoni explains.

She explains why early diagnosis is crucial.

"Unfortunately, the first diagnosis is most often made when the child is three to four years old, despite the parents indicating that there are some problems. The first alarming signs can already be seen between the months 14 and 19, such



as delay with speech, problems with movements (the characteristic movements of arms and legs), problems with the first cry, poor response to stimulants", says Ms Scattoni.

It is estimated that there are several thousand people with autism in our country, but nobody knows the exact number. There is no registry and that's why the system often does not recognize these people, so they cannot get help, social support, adequate health care, which is why they are called "invisible people".

Only in Nis there are around 500 people with disorders associated with autism, as it was said at the international symposium "Living with Autism from the Perspective of Patients, Parents and Professionals" recently held in this city and organized by UNICEF.

Delays in timely identification of early signs and problems of children with autistic spectrum disorders, insufficient number of centres for providing early interventions, and a lack of experts in this field, are just some of the problems Serbia is facing.

Serbia still does not have a strategy for resolving the problem of autism. There is ongoing preparation of the registry of children with disabilities, which is being implemented within the National Programme for the Development of Children in Early Childhood and which should be finished by the end of 2017.

What are the most important steps to take in the future to help parents and children with this problem in our country?

"Families are an important part of

implementing the solution. In other words, from our experience, the most important steps are to listen to the families in order to identify the most important priorities for them, and involve them in the multisectoral cooperation in order to develop sustainable and feasible programmes and practices", Andy Shih believes.

"Our mission is to promote solutions for people with autistic spectrum disorders and for their families, during the entire life cycle. Our main objective is inclusion of children and people in regular life activities", Mr Shih added.

Dr Milica Pejovic Milovancevic presented the results of the first-ever questionnaire on autism in Serbia – "The needs of parents of children with autistic spectrum disorders", which indicate that among children with autistic spectrum disorders in Serbia, 79 percent of them are male, and 21 percent female, that the concern for the child is first expressed by parents themselves, and not by a paediatrician, and that the first three most prominent characteristics, based on which they noticed the problem are – difficulties with other children, abnormal movements and not understanding parents. The diagnosis is usually made between the ages of three and four, and in most cases by a child psychiatrist.

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"Children with autistic spectrum disorders, on one hand, have no services or very limited services in small communities, and on the other hand, in big cities they are overwhelmed with different offers, with a substantial number of them having no grounding in science and

evidence of its effectiveness. That is why we need guidelines for diagnosis, treatment and strategies for education, i.e. providing additional support and help", said Milica Pejovic Milovancevic from the Association for Child and Adolescent Psychiatry and Allied Professions of Serbia (DEAPS).

The study concluded that it is necessary to empower and gather the key stakeholders in the community, to inform the wider community, including researchers and policy makers, about the needs of families and to have guidelines for development of priorities for addressing the needs of families. In addition to that, it is also important to improve the support in the education, health care and social care systems, to have intersectoral cooperation, to create guidelines for working with children and families based on examples of best practice and scientific evidence, and to improve the knowledge and skills of professionals working with children and families with autistic spectrum disorders.

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