Listener **by Maya Kulenovic**

Fact Finding Mission on Autism in Bosnia and Herzegovina

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kinder postzegels

Contents

Introduction

This report is the result of a Fact Finding Mission on Autism (FFM-A) in Bosnia and Herzegovina (B&H) in May 2010 (10-14 May). In this report I use the term autism and ASD (*Autistic Spectrum Disorders)*. interchangeably, in line with the DSM-V and the ICD-11 (both classification manuals on mental disorders, see References) expected in 2012/2013.

Autism is a very complex disorder. The core of the matter on a psychological level is the trouble in understanding *social interaction*; on a biological level the most complex aspect of autism is the *atypical maturation of the brain*, and the *slowness in making connections in the brain* (Delfos, 2005). In the new DSM-V and ICD-11 it will be classified under Cluster 2, *Neurodevelopmental disorders* (Swedo, 2009).

Autism for people themselves and for the people around them (parents, partners, family, teachers, employers) is very difficult to understand. Behavior of people with autism often amazes us, by the beauty of their behavior as well as by the sometimes very serious problems in their behavior that is often so different from all we know. Children with autism are very often bullied by their peers because of their behavior which seems strange or odd in the eyes of their peers.

Autism is in fact the most researched and least understood disorder there exists (Happé, 1999). The reason why it is so complex to understand, to diagnose and to treat is probably because ASD comes along with a broad *Mental Age Spectrum 1 Person* (MAS1P) within every person, child or adult, with autism (Delfos, 2005). This means that an adolescent of 17 years old calendar age can be 17 years old in biological maturation, 9 months in attachment, 3 years in play age, 1 year in time-management, 25 in mathematics and 35 in physics. This is what makes understanding and helping people with autism and their families so difficult. We cannot rely on automatisms in our behavior, because the child and later adolescent and adult surprises us with the behavior that seems so strange because it belongs to another mental age, and to many mental ages in the same person throughout every day.

Families with a person with ASD need help and understanding. They need to be listened to, to be respected in their own expertise and be helped to overcome their anxiety and sometimes panic which can lead to over-protective or even wrong help for the child (Groot and Delfos, in preparation). Especially when children with autism are not capable to communicate in words, parents are desperately looking for help. As autism help is yet very underdeveloped in B&H, this means that mainly the very severe cases where the person with ASD cannot or can nearly not speak, will be diagnosed. However, intelligence is independent from autism, and ranges from mental retardation to highly gifted, which complicates the situation of the child/adult and the family enormously.

The goal of the FFM-A was to find out what the situation with respect to autism/ASD concerning diagnosis, treatment and care in B&H is, in order to develop a plan for further helping building up autism/ASD care in B&H. The first step for this project came from Dzemil Vejzovic, born in Doboj Yugoslavia, living in The Netherlands since 1993. He is the founder of the organization Stichting Holland Hart Huis (NGO) with the sub NGO Primanatura in Doboj, situated in the north of B&H (see figure 1).

Figure 1: *The geographical situation of Doboj in the north of B&H (Map drawing: Nicolien van der Keur).*

Dzemil Vejzovic established a center there, the Holland Hart Huis, with the intention to work with traumatized women and children. He also wanted to develop autism help in Bosnia and Herzegovina to begin with Doboj. He wants to establish an expertise centre for autism/ASD in Doboj. The Holland Hart Huis first started as a center for traumatized women. The goal is to give them shelter when needed, offer them therapy and counseling, and help them develop work possibilities. Next to that Dzemil Vejzovic intends the Holland Hart Huis to develop as an expertise center for autism/ASD in B&H. After doing some research on autism experts in The Netherlands he asked me to help developing his goal. We developed the idea further and the Stichting Kinderpostzegels Nederland, in the person of Marian van Teeffelen, took up the idea and decided to subsidize a Fact Finding Mission on Autism in order to have a solid ground to develop autism/ASD help in the whole country of Bosnia and Herzegovina, building up from what is already working in there.

As developing help and care in a country is only possible with and coming from the people themselves, a week speaking with people, visiting organizations and universities was organized. For such a huge project as to develop autism/ASD help in B&H it is a condition sine qua non to work with the universities and expertise centers in the country. Moreover, a two way exchange would be the most respectful and would stimulate exchange, so I offered to give lectures on autism in three important university cities I visited (Sarajevo, Tuzla and Banja Luka), and organizations like centers for psychiatric (child) care. This idea was received with enthusiasm by centers and universities. The week was prepared by talking with experts, asking around and trying to find the key persons and organizations in the field. Many people helped me before and during the week in B&H, for which I thank them (see: Acknowledgements). Much information was yielded, though information on autism care was very limited, because help and care in the field of autism is terribly limited in B&H.

What I encountered in B&H, especially in the cities I visited - Sarajevo, Doboj, Tuzla and Banja Luka - were people who were dedicated to help other people, dedicated to work together and eager for opportunities to work on helping the people of B&H to have a better life, and do research to make a solid ground. They were very eager to know about autism/ASD, and many were struggling with the problems in diagnose, help and care that this particular disorder poses.
It is necessary to understand the situation and the infrastructure of B&H in order to know how to build autism help. Before presenting the facts on autism, I therefore present the situation of B&H, the fragmentation of the general infrastructure and the infrastructure of education to begin with.

Bosnia and Herzegovina

The Republic of Bosnia and Herzegovina was formerly a part of the Federal Socialistic Republic of Yugoslavia. The population count in 1991 showed a population of 4.5 million people in that part of Yugoslavia. In 2011 will be the next count (one count every ten years, but the count of 2001 failed). The 2011 count proves to be a politically sensitive subject. Population estimates go from 3.4 million to 3.8 or 3.9 people. About 1.2 million people left the country (which means 27% of the original population) and an estimated half a million people returned back to B&H after the war. Both the subjects of people leaving the country and the loss of people as a result of the war are sensitive subjects in B&H. But also internally there was a huge change, about 1.3 million people (29% of the population) had to leave their home, Internally Displaced Persons (IDP) (Campschreur, 2002). A study of the United Nations estimates that 60% of the population has been dispelled from their homes.

In most wars the refugees flee to escape from the fighting. In Croatia and Bosnia much of the fighting aims at making refugees (*The Economist*, 23 May 1992, In: Leyesdorff, 2008).

In 1992 the independence of B&H was declared and very quickly a war broke out. The war came upon the citizens of Bosnia and Herzegovina as a sudden wave of violence and anger not related to anything they knew before.
Many people fled from their country during the war. So did Maya Kulenovic, who was sixteen years old when her parents and she fled from Sarajevo, from Yugoslavia. She is a gifted painter, now living in Canada. Her painting *Listener* (see the cover of this report) functions in this report, and also during the FFM-A as a symbol for the people, children, and especially the children with autism, not being listened to.
Maya Kulenovic puts the traumatizing speed of the war coming over Sarajevo like this:

The notions of ethnical and religious differences between people in the city were a very new concept in the late eighties, when the nationalist rhetoric reared its ugly head and people started noticing the ethnicities of each other's names. At the same time, the erosion of socialism and it's fall left a pervasive feeling of failure; this got only worse after the country started falling apart. So the future of these people became uncertain, their identities were shattered, and what was offered to them instead, was of ethnic and religious nature, which most of them could not identify with. After the war begun, and the crimes were committed by neighbors and friends, a sense of disbelief and betrayal settled in. During the war, the suffering that they went through is well known - fear, hunger, death, disease, lack of normal social interaction and many experiences of brutality as well as compassion, *many from completely unexpected sources. Friends became enemies, and strangers ended up helping each other. The fabric of society was falling apart and being patched together from pieces. In those years, though, the city has completely changed. Huge number of people left, never to return, like my family. Their place has been taken by refugees from the rural areas, who were forced to leave their homes. As a result from this huge change in demographics, the spirit of the city as it was before the war, was transformed into something very different.*

Josip Broz Tito, called Tito, was the Premier of the Federal Socialistic Republic of Yugoslavia from 1945-1963, and President from 1953 till his death in 1980. After his death a huge power vacuum arose (Campscheur, 2002). The tension became translated in war activities coming from different parts of Yugoslavia. In fact the country was thrown back to all those centuries of war and suppression that characterizes the countries of the Balkan.

The political division which existed already before the republic was declared in 1943, came to the surface. Political figures tried to fit into the power gap from 1980 on. Suddenly, it was a country consisting of three different blood groups: Muslim, Serb and Croat. On the 15th January 1992 Croatia and Slovenia were acknowledged independence by the European Community after some fighting with the Yugoslavian army. The European Union invited the state Bosnia and Herzegovina to become independent too. For Bosnia and Herzegovina, an independent B&H would mean that the Serbs would become a minority, while they were the vast majority with a lot of power in the Republic of Yugoslavia (see figure 2).

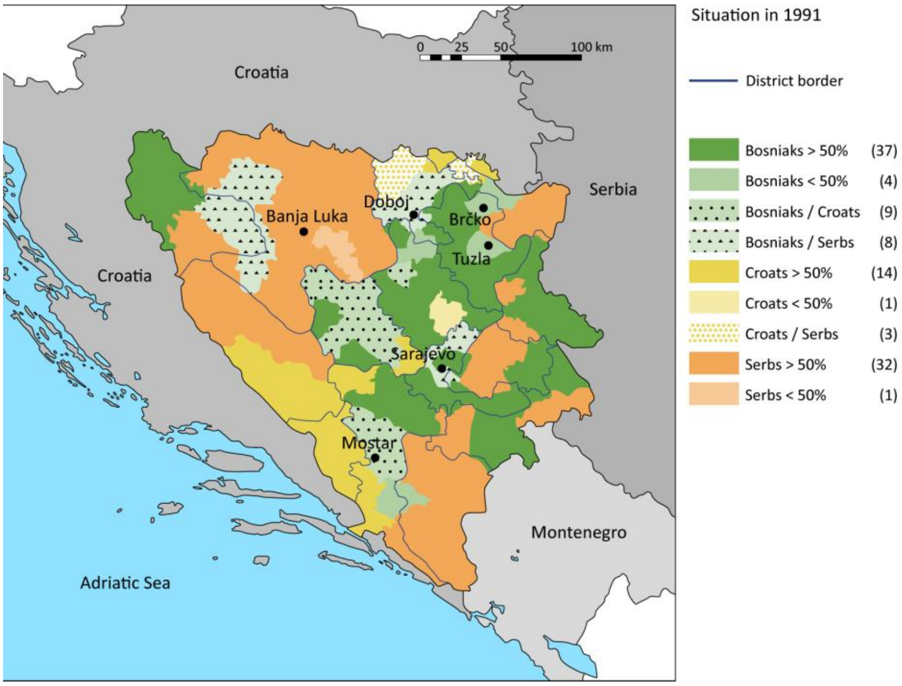

Figure 2: *The situation of ethnic majorities in the Bosnian-Herzegovinian part of Yugoslavia in 1991, with Muslims (Bosnjaks) as the majority (Map drawing: Nicolien van der Keur based on Campschreur, 2002).*

The population in B&H was living very mixed as can be seen in figure 2 where many areas are of a mixed nature: Bosnian-Croat/Bosnian-Serb/Croat-Serb (the terminology ‘Bosnian’ in this context is used to refer to the Bosniak population mostly Muslim, elsewhere it means the political term for inhabitants of B&H). This mixed society, living together is like what you would expect from what Maya Kulenovic says about people beginning *noticing the ethnicities of each other's names* only at the end of the eighties.

The choice for B&H was between independence and probably a war - because the Serbs were not expected to accept being a minority for the first time in history -, or else B&H could choose to join a smaller Yugoslavia where they thought they would be suppressed by Serbs anyway. By referendum they chose independence in 1992 (Campscheur, 2002). Through this independence the Serbs and Croats were torn apart from people with the same cultural background, Serbs and Croats: a border between two countries with inhabitants with the same cultural background, and speaking the same language (see figure 3). See also figure 4 to see the Croats in B&H living next to the Republic of Croatia, and the Serbs in The Republic Srpska next to The Republic of Serbia.

Figure 3: *Bosnia and Herzegovina amidst her neighbors (Map drawing: Nicolien van der Keur).*

Before the war, people of different cultural backgrounds were living all together in Yugoslavia, and then they were suddenly divided as a result of the declaration of independence in 1992, and the Serbs became a minority. The war broke out. Politicians stimulated fear and discrimination (Campscheur, 2002). In the war from 1992 to 1995, 250.000 people lost their life (4,6% of the population). The war was cruel, and people still wonder how this ultimate cruelty could happen. This cruelty found its devastating climax in the killing of some 7000 people, men, Muslim, in Srebrenica in 1995. A statistic that could not reflect the human impact of this figure. Guido Snel (2005, in Leyesdorff, 2008) describes it as follows: *From man they became Muslim*. The Dutch radio brings the following item in 2005: *In Srebrenica an estimated 7000 Muslims have been murdered*. Leyesdorff (2008) states:

Muslims? Many of the victims will not have been a practicing Muslim. But that is not the question. It is the effortlessness with which individual lives are wiped out. As if they were not fathers, not sons or *brothers, as if they did not have a profession, not have their own thought about the war, about the future, as if they had no memories of their parents and ancestors, as if they did not make plans for after the war, maybe to marry, maybe to divorce, maybe to begin a business when economy would restore a little bit, and to forget the hell of the enclave as soon as possible. As if they had not been individuals, angels or bastards, had not been brave house fathers or adulterers, but were Muslim from birth on, with the sole goal in life to be slaughtered in an ethnic conflict (translation Delfos).*

The war ended with the Dayton agreement of 1995, as a result of Nato activity. However, the tension between the minority of Serbs and the majority of Muslims in the new independent Republic of Bosnia and Herzegovina resulted in the division of the republic into two parts in 1996: the Republic of Srpska (which is a Serb majority) and the Federation Bosnia and Herzegovina with 10 cantons, all having their own government. In addition there is the district Brčko, that belongs to both the Republic and the Federation (see figure 4). In the new federation the three cultural backgrounds are still present: Muslim, Croats and Serbs.

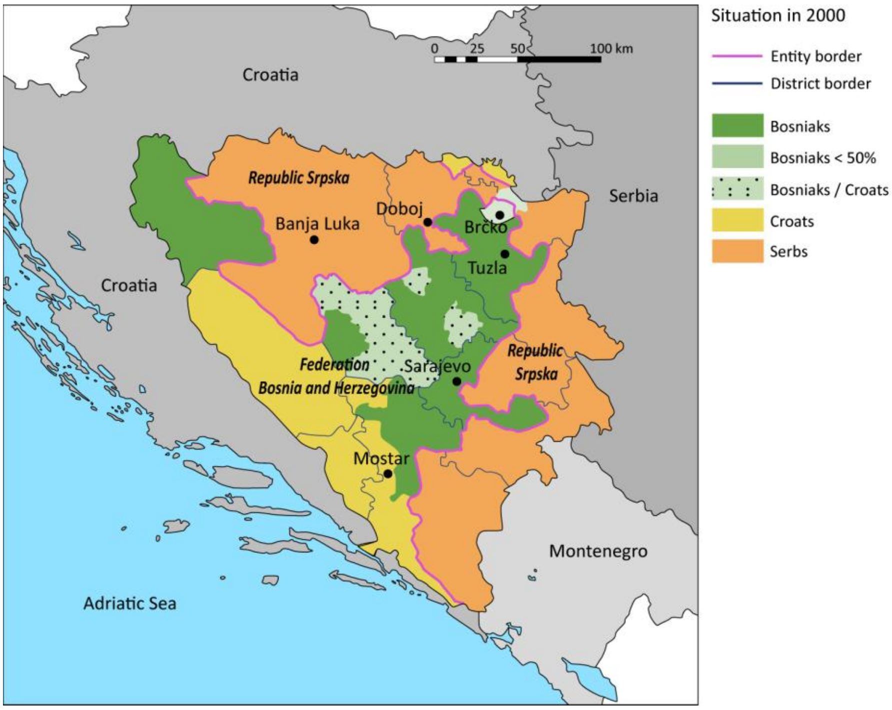

Figure 4: *Bosnia and Herzegovina with the Republic Srpska, the Federation Bosnia and Herzegovina and the district Brčko (Map drawing: Nicolien van der Keur based on Campschreur, 2002).*

To summarize, the falling apart of the Yugoslavian society, within some years, led to the construction of many independent states, republics: Croatia (1991), Slovenia (1991), Macedonia (1991), Bosnia and Herzegovina (1992), Serbia (2006), Montenegro (2006) and Kosovo (2008). The Republic of Bosnia and Herzegovina housed people coming from different cultural backgrounds. Shortly after the independence of B&H a new subdivision took place into a Republic and a Federation. This all adds up to B&H as a country in transition: people are trying to recover from shock, infrastructure and economy are destroyed for an important part, and it leaves the country ‘howling like a wolf’...

You cannot help yourself from thinking: How will people with autism experience this war and this post-war situation? Those people that have already so much trouble in understanding social interaction, how will they understand what happens to their world that is already quite complicated?

A fragmented society

The war left B&H with a totally fragmented structure. The Republic of B&H as an independent state is being controlled by the international community, through a High Representative. The state itself has a government consisting of a triad, three persons: a Croat, a Muslim and a Serb. Under this second governmental level there are a Republic (Srpska, 49% of B&H) and a Federation (Federation of Bosnia and Herzegovina, 51% of B&H) the last one divided into 10 cantons, next to these two entities there is the district (Brčko) belonging to both the Republic and the Federation. All parts have their own government with a president, government and parliament, taking their own decisions. The government of the state itself, the triad, has less governmental power than the two entities Republic Srpska and the Federation Bosnia and Herzegovina themselves. The saying goes that this governmental construction translated to the German situation would mean 80.000 ministers in Germany.
The whole infrastructure, as a consequence, is fragmented. There are general similarities, but the policies can differ from canton to canton and between the Republic and the Federation.
This very strange, over-organized political fragmentation reflects the underlying lack of security as a result of the fast war. Maya Kulenovic describes it very sensitively as follows:

One thing that may be in common with most people who were affected by war, is an experience of chaos: a complete lack of law and break down of most of the society systems. There are few other things that can make a person feel as alone and exposed, as this. This is also something that cannot be forgotten or healed from, since it is a form of knowledge about human nature. Afterwards, it is hard to ever see ordinary people, or friends in a completely casual way. Myself, I haven't seen much of the war first hand - a few weeks only, but I still can't help questioning: How would people I meet behave in a situation of life and death? Would they sink to the ultimate levels of cruelty? Would they betray, or would they keep their humanity and decency? So it becomes almost impossible to trust anyone, or any situation, and it is hard to feel secure.

Social inclusion is an important problem in B&H. The National Human Development Report of 2007 (NHD, 2007) suggests that over 50% of the population is socially excluded. Among the most vulnerable are the elderly, persons with disabilities, displaced persons, the Roma, the families with two or more children, the unemployed and the low-skilled youth. Women are particularly at risk in all categories. The National Health Report on Social Inclusion in B&H puts it as follows: *At the heart of these problems, we believe, lies a dysfunctional political system, which re-produces what we earlier described as an 'ethnicization of public life'* (NHD, 2007).

The fragmented organization can be felt in everything. It shows itself on an economic level among others in the loss of industries, 70% of the industries from before the war have been destroyed (European Commission, 2008). The fragmentation is felt in the different policies for every subject, in the fragmented Health care, in fact it penetrates every aspect of daily life. People depend of the hospitals in the near surroundings, and from the equipment they have. Zagreb (Croatia) and Belgrade (Serbia), both important cities in ex-Yugoslavia, are still important for all the facilities that do not exist in B&H, or that exist on a lesser level of development. Fragmentation is also felt on a human level, people trying to make a living, though 44 % are said to be registered as unemployed, the real figure would be 29% according to the European Commission (European Commission, 2008). Poverty is an important issue, and particularly women are at risk. People from universities also told me the suicide rates feel as very high as they experience it around them, though there exist no statistics about it.

On the level of specialist care the situation is even worse, and little cooperation exists between the different universities, and also with and between expertise centers. Many specialist centers have vanished as result of the war, so many specialists find themselves without possibilities to do the work they were used to do before the war, and in the meantime eighteen years later, the expertise often has been lost for the field.

The infrastructure of education

The infrastructure of primary and secondary education differs from European standards. The school system consists of 9 grades. Children enter school at the age of 6. Pre-school education, before the age of six, is not obligatory and only 2% of children attend pre-school institutions. Schools have their school pedagogue who tests the school level of children on different subjects, who makes plans for special education for children with special needs, and who works with teachers on their monthly education plan for the class.

Children go to school for half a day, several hours a day; some years in the morning, other times in the afternoon. Children receive homework for the rest of the day. A school building often accommodates two shifts. There are many divided schools, which means that there are two schools following different curriculums (usually Bosnian and Croatian) under one roof, sharing premises. There is a summer vacation of 2.5 months and another month vacation in the winter, besides the shorter vacations of a week or so during the school year (public/national holidays/religious celebrations). Books are very costly and parents have to buy the schoolbooks themselves. The parents have the responsibility for the homework of their children and for the long vacations. Compared to many countries, the education of children in B&H comprises less time at school. For the future the intention is to have one shift per school, but that would mean the construction of as many schools as there already exist in B&H. The idea of children receiving education the whole day at school, and all children being able to receive education, is still planned further on in the future.

In the rural areas children very often are not able to attend schools. There are no buses to bring children to school, and the situation is not secure enough. Parents cannot always help their children in the sense of giving school education themselves, because they are often analphabetic themselves. Also, it is not rare that parents choose to send their sons to school before the daughters are given this opportunity. The gender issue is an important one in B&H.

Something that complicates much the continuation of education is that during the war, many people of the rural areas had to leave their houses and fled to the cities. As a result the schooling of many children and young people who are adults now, was disrupted.

The use of educational material is said to be quite conservative, and material is limited and quite costly. There is a lack of experts in the field of advanced, modern methods of education. As a result,

many schools are left with quite a challenge to implement inclusive education, that is acceptation of each child in the school, with adaptation to the special needs of some children.
The government of the Republic of B&H wants to implement the Salamanca agreements on *inclusive education*, meaning to give all children the possibility to attend a regular school. To make inclusion possible for children with special needs, the law allows teachers to get an assistant teacher in the classroom for children with a diagnose. However, this rarely happens in practice.
From 1997 till 2002 Vasilija Veljkovic (Médecins du Monde) assisted the Duga Association (Veljkovic and Rouse, 2001) in Sarajevo, to develop the *School Based Project for Children*, and implemented this in 23 schools in B&H. With this project 'good practices' from other countries were implemented in B&H. The goal of the project was to reconstruct special education classrooms, to educate parents and teachers who worked in these classrooms, and to provide expert support and treatment to children with special needs. After the project was finalized, these schools continue to present the core of inclusive education in the country. Most of them have either special education classrooms or workshops for children with severe difficulties. At the end of the project, after expert support, 40 pupils were able to transfer to regular classes. Martyn Rouse (Cambridge University) evaluated this project and provided some of the trainings for participants.

To summarize, not all the children can attend school due to the bad infrastructure, and when they attend school it is in general not before six years old, unless their parents are able to pay for preschool care and preschool education. Children attend school for half a day, several hours a day, and are expected to do homework the other half of the day. Education, as a result, lags behind in possibilities for children compared to the West European countries. For children with autism this educational situation is especially difficult. Most children with ASD are not included in the educational system. There exists only one autism unit in a special school in Tuzla, and a preschool unit for children with autism in a special school in Sarajevo.

Gathering facts

In order to be able to gather facts, organizations in The Netherlands and in B&H asked about people working with children/adults with autism, and the specialists in trauma help in B&H. Already from The Netherlands and later in B&H itself, I myself asked around too. At a certain moment the same names popped up, and it became clear that the most important people and organizations seemed to be inserted in the FFM-A program of one week. Especially Marian van Teeffelen from Stichting Kinderpostzegels Nederland and my interpreters during the week in B&H, Adela Hadziomerovic and Otmar Svetlin Dzaferagic, both working for FICE (International Federation of Educative Communities) B&H, were very helpful to find the right persons and institutions.

In table 1 the organizations and people met during the FFM-A (10-14 May 2010) in B&H are shown. In the last column is marked whether I encountered them in a meeting, and if they attended a lecture given in a university or an expertise center. After lectures there also was exchange possible.

Organization	**City**	**Function**	**Name**	**Lecture/meeting**
International University Sarajevo, IUS, *FASS, Faculty of*	Sarajevo	Child psychologist	Prof. Dr. Senija Tahirovic	meeting and attended lecture
		Dean FASS	Assoc.Prof.Dr. Ali Guneşş	meeting and attended lecture
		President of the Board of	Prof.Dr. Adem Bastürk	attended the lecture

Arts and Social Sciences		Trustees of IUS		
		Students		attended the lecture
		Teachers and professors of IUS		meeting and attended lecture
		Professionals from the field of trauma and autism	Among them: Marina Nezirovic, project coordinator from Duga	attended the lecture
University of Tuzla *Faculty of Education and Rehabilitation; Faculty of Psychology*	Tuzla	Pedagogue	Contact: Mr. Sci. Dr. Selma Hodzic	meeting and attended lecture
		Students		attended the lecture
		Special School pedagogue, autism unit	Damir Muratovic	meeting and attended lecture
		Teachers special school		
		Professionals from the field of trauma and autism		attended the lecture
Banja Luka University *Faculty of Psychology*	Banja Luka	Clinical psychologist	Assis.Prof. Dr. Nada Letic	meetings and attended lecture
		Students		attended the lecture
		Professor and teachers		attended the lecture
		Professionals in the field		attended the lecture
		Parents of children with autism		attended the lecture
Vive Žene	Tuzla	Director	Jasna Zecevic	meeting
		Child psychologist	Augustina Rahmanovic - Koning	
Duga	Sarajevo	Director	Anka Izetbegovic	meeting
		Project-coordinator, UK education.	Marina Nezirovic	
Primanatura	Doboj	Coordinator/Director	Dzemil Vejzovic	meeting and attended lecture
Social Service Doboj	Doboj	Coordinator /Director	Dzemil Vejzovic	meeting and attended lecture
		Social workers		attended the lecture
		Teachers		
		Pedagogue		
		Logopedist		
		Pediatrician		
		Other professionals		
Primanatura, Holland Hart Huis	Doboj	Coordinator /Director	Dzemil Vejzovic	meeting
		Workers with the children with disabilities and their parents	Vesna Vukmirovic Aleksandra Djuricic Sladjana Neskovic	
Special school 1	Sarajevo		Mirsad Asimovic	meeting
Special school 2 Centar Vladimir Nazor	Sarajevo	Director	Zulfo Ahmetovic	meeting, visit of the school
		Teachers School pedagogue		
Regular school , Kovacici	Sarajevo	Director	Almina Corovic	meeting
		Project coordinator Duga	Marina Nezirovic	
		School pedagogue		
Special school, autism unit	Tuzla		Damir Muratovic	meeting, visit of the autism unit
Hospital,	Sarajevo	Child psychiatrist, autism	Nermina Curcic	meeting

Psychiatric Ward		diagnose unit		
		Child psychologist	Alma Pasalic	Email exchange
Hospital Child Psychiatric Ward, autism diagnose unit	Banja Luka	Psychiatrist Psychologists Social workers	Among them: Mira Spremo Tatjana Markovic Maja Sinikovic	meeting and visit of the psychiatric ward and attended the lecture
Psychiatric Hospital	Banja Luka	Psyciatrists, Psychologists, Social Workers, staff, director Psychiatric Hospital	Among them: Mira Spremo Tatjana Markovic Maja Sinikovic And many others	lecture
Clinic of Child Diseases, Child Neurology department	Banja Luka	Clinical psychologist	Nada Letic	meeting and visit neurological ward and attended the lecture
		Child Neurologist	Ella	
		Professionals from the clinic		
Speech center	Banja Luka	Director Speech center	Zeljko Mrda	meeting
		Teachers, parents and professionals		
Sign, Gender	Sarajevo	Director Sign and parent of child with autism	Lejla Somun-Krupalija	meeting
			Kika Dzaferagic	
Association of parents of children with autism: Urdas	Sarajevo	President of the association	Veselinka Moric	meeting
Dutch Embassy	Sarajevo	Deputy Head of Mission/ Head of Development Cooperation	Riny Bus	meeting
Different organisations	Banja Luka	Professionals: Psychologist School pedagogue School pedagogue Director Speech Center Personal assistant Personal assistant Logopedist Coordinator CNFCEE	Among them: Nada Letic Gordana Kecman Angelina Zeljko Mrda Branka Gligic Branka Ivanovic	meeting

Table 1: *The organizations and people met during the FFM-A in B&H.*

With many people an intensive e-mail correspondence took place after the FFM-A and with some whom were not present at that moment in one of the cities we made e-mail contact afterwards and gathered more information.

Autism and organization of autism help in B&H

Autism/ASD has a stable prevalence all over the world, independent from culture, from serious to mild autism. The statistics range from 60 (Chakrabarti et al., 2005) to 116 (Baird et al., 2006) persons with ASD in 10.000 people. For B&H, estimating the prevalence will depend from the population count expected in 2011. On a population of 4.5 million people before the war, it would be ranging from 27.000 to 52.200 people with autism (young and old). After the war, and with the estimated 1.2 million persons who left the country and an estimated half a million coming back, the question is how many persons with autism are left in B&H at this moment. There are no statistics about this, but it is probable that in the population that fled the country the prevalence of persons with autism could be smaller because it takes quite some organization capacity and quite some knowledge of social interaction to be able to flee and find another situation to live in. Children with autism are often extremely anxious to change their situation and resist actively to change. This could make it very difficult for parents to go out of the country. If a change of prevalence is to be expected from the war that would probably mean more persons with autism on 10.000 people in B&H than before the war. This means that the statistical estimation based on the 4.5 million people before the war is perhaps still correct, notwithstanding the changes in population as a result of the war.

In table 2, the statistical translation of prevalence of autism according to the real and an estimated population count is shown. As already mentioned before, there exist three estimates of the number of people living in B&H in 2010: 3.4; 3.8 or 3.9 million people. The estimation of people with autism is calculated from the idea that the same – universal - prevalence of persons with autism per 10.000 people exists before and after the war. This estimate does not take into account the above mentioned change in population in favor of people with ASD as a result of the war stream of refugees.

year	**Population in millions**	**Prevalence (60/10.000) from**	**Prevalence (116/10.000) to**
1991	(real) 4,5	27.000	52.200
2010	(estimated) 3,4	20.400	39.440
	(estimated) 3,8	22.800	44.080
	(estimated) 3,9	23.400	45.240

Table 2: *Estimated prevalence of persons with autism/ASD for the different (real and estimated) population counts in B&H. Calculated from the two prevalence rates (60 or 116 in 10.000), thus ranging from column 3 to column 4.*

There exists differences in prevalence for boys/men and girls/women with ASD. Male persons are much often afflicted than female persons, depending on the severity from four to ten times as much men than women: 4 (m) : 1(f) to 10(m) : 1(f).

Little is known about the organization of autism help before the war. Institutions that were active in autism help before the war no longer exist. Many of the professionals who were active before the war lost their job at the institution they worked for. As the war is already 18 years ago, experts from before the war have grown older, and much expertise seems to be lost. Probably latent expertise is still available in those persons who probably found another profession since the war. Many professionals still live somewhere in the country, aging now from early forty to their late seventies, if we take an age of 25 years old at the beginning of the war as the youngest professional with some expertise on autism and 65 as the oldest expertise age at the beginning of the war. Because of the *brain drain* as a result of the people who fled during the war (an estimated 1.2 million) probably much expertise has left the country without returning (only an estimated half a million returned after the war). It is not known if, and how many of them had expertise on autism/ASD. Not only many people fled the country, but a substantial part of the population left their houses and became *Internally Displaced Persons* (IDP). So, much of the expertise in many fields has been lost or scattered throughout the country. An expertise 'harvest' to find the expertise still existing somewhere in B&H still seems to be called for and sensible.

Also, since 1992, the scientific knowledge about autism changed. The old idea which supposed that autism was caused by the education of the parents, particularly the mothers, has been outdated by the findings that autism has a very serious gene component (Delfos, 2005). Diagnose and treatment of autism/ASD is nowadays directed to the genetic source, and the search is for biological markers, especially to enable *early intervention* (Servatius-Oosterling, 2010).

All this means that the expertise has to be build more or less from scratch on. However, the dedication to this field I encountered in B&H, is very strong. Professionals and parents are looking desperately for methodology, instruments, treatment models, diagnose models, intervention models in general, and how to cope with the strange and often difficult behavior of children with ASD. This is why I try to be as elaborate and at the same time as concise as possible in this report, to enable expertise enhancement already by presenting the facts in a comprehensive way, as much as it is possible within the limits of a report like this one.

In B&H there are several complications when speaking about autism. Of course a huge problem is that there is no organized support network for children and families of children with ASD. At the organizational level children with ASD are not represented at the entity-level of Coordinating Committees for Persons with Disabilities. There is nearly no public awareness about autism.
But it all begins in the family. Raising a child with autism is quite a challenge. For parents it can prove to be very difficult. As to mutual help from the extended family, neighbors and other persons this again proves to be a problem because already building a secure group as such is difficult for most people in B&H, as social inclusion is very limited (NHD, 2007). This very limited social inclusion works very bad for families with a child or an adult with autism. Those families generally already suffer from social exclusion because of the difficulties with their child or adult with ASD. They need people around them badly, but it is not easy to organize a stable group around them, even family members are often not supportive enough, because the behavior of the child is not understood. The extended family and people around the family with the child with autism are often wondering if the child's behavior is not due to bad education. They blame the parents and the parents feel very alone with their problem (Groot and Delfos, in preparation). Fathers too often blame mothers, which is quite a burden in the relation and presents a reason for divorce. A specific problem for B&H is that many families have been broken through the war. In many families the father died and the mother is left alone to raise her children. Many families had to leave their home during the war, and many families are far away from their extended family or lost them. People have to build new social environments in their new life in another place after the war. Families have still to recover from this situation.

Parents of children with autism have trouble organizing together. Some initiatives exist, for example the Association of parents with children with ASD, Urdas, in Sarajevo with some 25 families who are member, and the association of parents of children with autism in Tuzla. In Banja Luka the parents association is not so well developed yet and parents do not feel very secure about professionals. Before the war, expertise centers on autism existed and daily care centers functioned, but they are not operational any more. So, parents of children with autism do not easily come into contact with each other. The same applies to schools. Children with ASD mostly are not included in the educational system, although there are governmental policies on inclusive education, still there is no systematic approach to this problem. It depends on the good will of some individuals, school teachers and pedagogues. Because of the fact that many children with ASD are not included in education, and cannot attend schools because of the limited infrastructure, parents do lack support through education and this also effects information sharing. Internet too, is not yet widely spread, so parents cannot easily reach information on internet. But when they can, they lack the knowledge and experience to assess the value of the information they find on internet, just like was discovered when working with the parents in Ecuador (Groot and Delfos, in preparation).

The educational system of some hours a day leaves parents with the care of the child for most of the time, and most of the children with ASD do not even attend school. The help of a child in the school system is quite intensive, and certainly in the more severe cases of ASD it takes one teacher/one pupil to help children with autism in the educational system. But this is also true for daily care. Bringing up a child with autism requires a lot from the people around the child. One parent I met works with the Sun Rise method, which takes a group of intensively working volunteers around one child, but that is quite an exception.

There is a strong need for expertise on autism. There is a total lack of systematic solutions, services and professionals in the field. There are two centers in B&H who can respond to a request for a diagnose of ASD. These are: 1 the Neuropsychiatric Ward in the Hospital of Sarajevo, and 2 the Clinic of Child Diseases in Banja Luka working together with the Child Psychiatric Ward of the Psychiatric Hospital in Banja Luka. There is no systemic data collection available yet on number of diagnoses. In Banja Luka they are just starting. In Sarajevo they think that the amount of requests for diagnose are up to 40 to 50 a year. As for treatment the situation is even worse. The parents association in Sarajevo works hard to have professionals come from America to train parents and professionals in B&H. Most requests for a diagnose of autism are children that have already been diagnosed by psychologists and pedagogues as probably having an ASD. The Psychiatric Ward is then asked for a confirmation of the diagnose. Most of them are children who have a speech problem and cannot speak, or only a few words. Asperger syndrome, mild ASD, without speech problem is seldom diagnosed. Prevalence, however, shows that most cases are without speech problems, and without mental retardation (see figure 5 below). There is no system of early detection, diagnosis or intervention in the field of autism. Parents turn to specialists in Zagreb (Croatia) and Belgrade (Serbia) for a diagnose, because of the enormous lack of specialists in their own country.
One of the problems with ASD is that there exists the risk of epilepsy, certainly during the preschool years and during puberty (Canitano, 2007). But epileptic behavior, certainly 'petit mal' and 'absences' are not easy to detect. You need neurologists to examine children thoroughly to confirm epilepsy. In Sarajevo and Banja Luka a neurologist is part of the multidisciplinary team.

To summarize: Diagnosis, treatment, education and day care are needed for children with ASD, and are lacking on a large scale. Expertise centers, diagnose centers, treatment facilities, professionals specialized in autism, daily care centers, special schools are also lacking on a large scale. There is a total lack of systematic solutions, services and professionals in the field.

Autism, trauma and misdiagnose

It is not always easy to discern ASD from other disorders or problems. The Rumanian orphanages where the neglect of children was very serious, showed us that children could be mistakenly be diagnosed with ASD when in fact the source of their *autistiform* behavior was *neglect*. Autistiform means *not* autistic, but *seemingly* autistic behavior. Michael Rutter developed the term 'Quasi Autistic Pattern (QAP)' to describe children with autistic behavior that had no ASD at all; Federici spoke of the Institutional Autistic Syndrome (Rutter et al., 1999; Federici, 1998). But not only neglect is a source for possible misdiagnose of ASD. Autism comes with some behaviors that can be displayed by children in difficult situations. Behaviors as withdrawal from social interaction, and trying to recuperate from social interaction by creating its own world are behaviors that can be found not only in children who suffer from neglect, but also with children suffering from trauma. This is especially the case for the forms of ASD called 'Asperger syndrome' in the DSM-IV and ICD-10, what would perhaps be called mild ASD in the new editions DSM-V and ICD-11. So, if diagnose of ASD develops in B&H like it does in other countries, and this is already happening, the mild form of ASD will become the center of focus. Most people with ASD have no mental retardation, but normal or above normal intelligence and can speak (see figure 5).

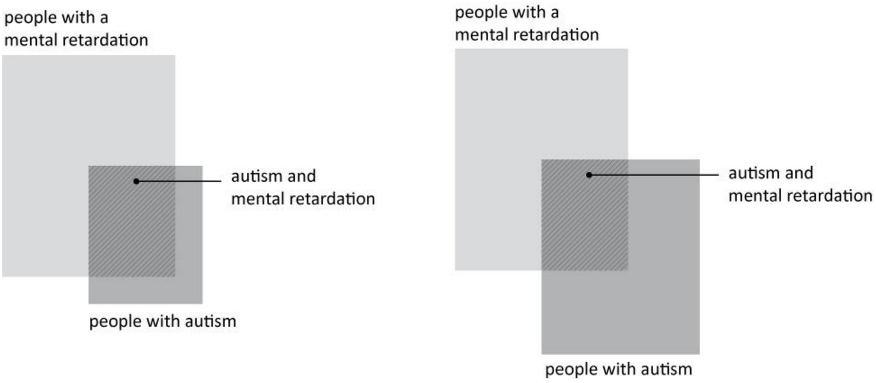

Figure 5: *The shift in recognition of prevalence of ASD. Left: it was thought that autism mostly occurred along with no speech and with mental retardation, three quarters of the people with autism were believed to have a mental retardation disorder. Right: Nowadays we discovered that three quarters of people with autism have normal or even higher intelligence and no mental retardation* (Delfos, 2005).

It is particularly where the ASD goes together with normal intelligence and normal speech that the risk of misdiagnoses becomes a problem. Trauma being one of the possible sources of *autistiform* behavior without being an ASD, diagnose is especially difficult in this case. Trauma is very wide spread in B&H, and this means that at one hand there is a lot of expertise on trauma in B&H, and at the other hand if we do not take care, misdiagnose of trauma or ASD could become an important pitfall. That is children diagnosed as suffering from trauma being diagnosed as ASD, and children with ASD being diagnosed as suffering from trauma. There still exists no diagnostic tool for the Quasi Autistic Pattern (QAP), but there is a strong need for it (Prof. Dr. Michael Rutter, personal communication).

If the subject is not addressed correctly, a 'tsunami' of diagnoses could be the consequence. It is already what we see happening in many well developed countries, not even suffering from trauma.

Here ends the reproduction of the facts on ASD/autism in B&H. The situation does not present itself very optimistically, yet new possibilities present themselves, and professionals all over the country are very eager to develop help in this area.

Translation of the FFM-A into recommendations

The result of the FFM-A presents a sad situation for children, adolescents, adults with ASD and their parents and environment, but there are circumstances that can be considered protective factors:
1: It seems just the right moment for B&H to start building up ASD expertise and help.
2: In the world the traditional knowledge on ASD is being shifted towards the recent bio-psychological knowledge and translated into the new manuals. B&H benefits from lessons learned on ASD in other parts of the world.
3: There is a lot of knowledge in B&H on trauma, which could help to prevent misdiagnoses of ASD.
4: People are eager to work together and are seriously interested in ASD.

In 12 points I try to translate the situation on ASD in B&H into recommendations to build up autism help for the country. It is quite a list, but the situation is poignant. Much is to be done, but much is possible too. The situation at the moment seems to be very fertile, perhaps even just the right moment. People want to connect, and want to work together. Much of the points below is about children, but autism is a lifelong disorder. Help and care for adolescents, adults and elderly people is also needed. The start has to be with the children. But this shall have to be extended to adolescents and adults too. Now and then, the lifelong scale is mentioned in the points, but it has to be kept in mind with all the points.

The guiding rules for developing ASD help in B&H should be:
A: Empower parents
B: Train professionals
C: Develop expertise, treatment and daily care.

1: *Diagnosis*
At the moment diagnosis of ASD is situated in two centers: the Psychiatric Ward in Sarajevo, and the Child Psychiatric Ward in Banja Luka together with the Neurology Department of the Clinic of Child Diseases in Banja Luka. In the country there are some psychologists and pedagogues that can recognize ASD and prepare a request for diagnose in a center. Parents often go to Zagreb or Belgrade to have their child diagnosed. Both cities work as a confirmation of a diagnose in B&H. Getting a multidisciplinary diagnose on ASD is rare, and not too far from where you live in B&H is nearly impossible. When you live in Sarajevo or Banja Luka it is somewhat easier, but Banja Luka is more or less starting as a center for diagnose. There is no general system of diagnose in B&H. The Health Care is not organized in a sense that all children have youth health care from birth to 19 years, like in the Netherlands. This means that there is no infrastructure to help to develop early detection of ASD. It would be important that information about early detection is spread in order to enable parents and professionals to diagnose and help children at an early stage. Health care is not well organized and is very costly. Not everyone has access to Health care. So diagnose and help is rather limited to the wealthy families. So, most children with ASD are not close to being diagnosed, and live in often very difficult conditions at home, with desperate parents not understanding what is happening with their child.

Recent research (Servatius-Oosterling, 2010) showed that for early detection of ASD the ASD questionnaires were not very discriminative. The most useful in detecting ASD was the ADOS, the *Autism Diagnostic Observation Scale Schedule*, certainly with the new developed algorithms (Lord et al., 2001). Observation proves to be a very important method for early detection and for diagnose of ASD in general. At the moment observation is one of the most important ways to diagnose ASD in B&H. It would be a huge step forward to be able to do structured observation. The ADOS is probably also useable for the new DSM-V and ICD-11 classification. A translation in Bosnian and validation is indicated. There is a developmental test in Croatian, the Čuturić, validated for a B&H population by. Research could help discover if this test would be useable in the diagnose of ASD, and particularly for the dimension intelligence and for assessing the MAS1P (mental age spectrum 1 person). This is important, because in the DSM-V to come, a diagnose of ASD would engender more aspects, among them development and intelligence.

The Clinic of Child Diseases in Banja Luka does MRI measurements, and EEG measurements as a standard procedure for children older than two years. Before that age the examination is too invasive. This examination is not only helpful in diagnosing *epilepsy*, but also does it given an indication of the *maturation* of the brain, which will probably be one of the biological markers in the future. ASD will be classified in the new DSM-V under *Neurodevelopmental Disorders* (Swedo, 2009) The neurologist of Banja Luka already made clear that in the case of severe autism the EEG showed a less matured brain than with Asperger syndrome, ASD-mild form. These examinations will remain important in diagnosing ASD and exclude other neurological and neurodevelopmental disorders. It is clear that these possibilities are not available all over B&H, even if there are enough child neurologists to handle the requests now, in the future this will have to be taken into account and probably present a serious problem.

For an ASD diagnose a multidisciplinary team is necessary (psychiatrist, neurologist, psychologist, pedagogue, social worker).

To develop good diagnostic systems, it would be advisable to train child psychologists and special pedagogues in preparing a request for an ASD diagnose. A structured observation scale like the ADOS could be used. Professionals could be trained to make camera recordings of typical behavior of the child. This could be helpful in preventing the enormous waiting lists that will perhaps develop like in all countries where autism help is being developed. Instead of authorizing psychologists and pedagogues who are not trained or specialized in autism diagnosis to perform a diagnose to resolve the waiting list problem, it would be wiser to begin training them, because the problem of diagnose already shows itself in B&H.

When children are diagnosed, normally people begin to understand ASD and recognize ASD or ASD-traits in other family members. As a result the call for diagnose of family members augments. In most countries the diagnose of adults with ASD is in full progression now. It would be wise for B&H to be prepared for this and develop diagnose methods for adults as well.

One of the problems one encounters in diagnose of autism is the risk for misdiagnose, certainly false positives, that means a diagnose of ASD in the case of no ASD in the child or adult. It is important to make the difference between ASD and Quasi Autistic Pattern (QAP) (Rutter et al., 1999). There yet exists no instrument to diagnose QAP and there is a need for such a tool (Rutter, personal communication). In a country where trauma plays an important role, the need is even more acute. The knowledge on trauma is quite developed in B&H (Dahic and Zecevic, 2008; 2009a; 2009b). The construction of an instrument for the diagnose of QAP in B&H would be very sensible and a contribution to diagnose of ASD and trauma all over the world.

To summarize: The country is badly in need of a systematic procedure with different validated instruments to diagnose ASD. Universities in B&H could play an important role in developing and validating instruments. ASD should come into public awareness and information on what autism means and the possibilities for diagnose should be widespread in the country. A system of trained psychologists and pedagogues with social workers that can prepare a diagnose of ASD should be developed. The risk of misdiagnose should be faced and instruments developed and validated, to prevent misdiagnose.

2: *Treatment*

There is no cure for ASD, only treatment to optimize development, and help child, family and school to enhance the quality of life, to develop where one could not imagine it would be possible, and to get the children out of their often very difficult situation. When help began to be developed in Peru, adults with autism were discovered living under very sad conditions. Some parents were so desperate and so afraid of the behavior of their child/adult that they tied them up on a chair during the day, to prevent them from hurting others and themselves. The anxiety in the child/adult was augmented enormously with this treatment, and his behavior became more and more aggressive. When he was treated in the autism center, and parents were told what the autism meant and what could be dome, the same man was able to work in a mall, and was very happy.

It is not a choice for parents or teachers to repress, it is a lack of knowledge how to cope otherwise with very difficult, and even dangerous situations. The *psychological approach* instead of repression is something people can learn. In the University of Tuzla, the professionals were very eager to learn this, when they discovered what it meant when speaking about cases that were put before me. They asked for a training of the professionals in the psychological approach.

ASD is a very complex disorder. So, once a diagnose, the treatment is not simple. There is no medication that helps in the case of ASD, only for side effects like epilepsy. As there is yet no structural help of any kind in the case of ASD, from diagnose to school education in B&H, there exist nearly no treatment possibilities of ASD in B&H. However, the problem is that the question of valid treatment for ASD is a worldwide problem. Many treatments try to combine elements, but do not address the core problem (Delfos, 2010). A newly developed training for young children with ASD to develop 'joint attention', does not have the effects one would expect (Servatius-Oosterling, 2010). A lack of joint attention is a typical problem in social interaction with children with ASD. *Joint attention* is a coordination of attention between a child and another person, looking at a person, an object or an event, in which both parties are aware of the attention focused and shared. For example, mother and child look together at the ducks in the pond and they are both aware that the other looks at the same thing.

The most widespread important treatment with a long tradition of research at the moment is: *Applied Behavior Analysis* (ABA), based on small steps, Discrete Trial Training (DTT). Some other methods are Precision Teaching, Pivotal Training, STEP, and Sun Rise. The last one works with changing the environment of a child with ASD and it needs a group of many volunteers for one child. Most therapies are developed for the more severe forms, particularly for children who do not speak. Very little is developed for the mild forms of ASD.

In Ecuador a relatively new treatment is used in working with children with a severe form of ASD, with no or very little speech communication which is also valid for working with people with mental retardation (Groot & Delfos, in preparation). This method, Basic Experience Network (BEN) works with developing the person with ASD from the perspective of a lack of maturation and the aim is to stimulate this maturation. The method needs to be developed further for less severe forms of ASD, and refined, but the aspect of adapting to delayed maturation is a very important one (Delfos, 2005) and fits in the new DSM-V/ICD-11 that classifies ASD in cluster 2, Neurodevelopmental disorders (Swedo, 2009), that is about the maturation of the brain. The idea of delayed maturation and progression of maturation requires an adapted form of treatment for each individual (Delfos, 2005). In order to do so, an age spectrum (MAS1P) for each child on several subjects must be assessed.

To summarize: In B&H there is no treatment and there are no professionals specialized in treatment of ASD. Parents import professional help from outside the country, particularly America. This means that it is only available for wealthy parents. It is necessary to develop the availability of a spectrum of treatments that have the best fit for persons with ASD and the family. Professionals should be trained to be able to give the treatments. Public awareness should be developed as to the possibilities of treatment of ASD.

3: *Day centers, daily care*

There have been no day centers for children with ASD, no treatment centers in B&H for a very long time. The centers from before the war have disappeared. In Doboj in the Holland Hart Huis a care center started for children with ASD and children with other special needs. One of the theoretical questions is whether children with autism should receive care in the same center as other children with special needs. The best answer to this question seems to be that they should be alternating mixed and separate groups. Children with ASD need intensive special treatment, different from other children. But they also need experience in socializing with peers. This means that a center should be organized in a way that both possibilities can alternate.

Autism is a very complex disorder. Because of the broad spectrum of mental ages within a person (MAS1P) with ASD (Delfos, 2005) it is the most difficult disorder to deal with. Children with ASD seldom attend school, so the burden of taking daily care of the children with ASD is largely on the shoulders of parents. For most parents this is an exhausting and often desperate situation. The extended family very often has trouble understanding the educational situation of the parents. So parents often cannot easily rely on their family. In B&H the situation is even more difficult because of the very limited social inclusion (NHD, 2007).

The daily care of children with ASD, certainly the severe forms, requires a lot of investment of people around the child. It is not comparable with a child with Down syndrome for instance, who needs much care, but not as much as a child with ASD. The development of day centers, is of utmost importance. Perhaps even more important is the psycho-education of families, the extended families of persons with ASD. The psycho-education helps understanding ASD, the needs and qualities of that specific child, and enhances good communication between the person with ASD and the people around him or her. Guesthouses where children can stay sometimes for the weekend or during vacations are important to make possible that families can continue without getting exhausted, and also for the children to meet peers like them. Psycho-education for professionals could help them assist the child and the family. Programs of psycho-education for (extended) families must be developed and available throughout B&H. Participation of parents in the day centers would be positive for the relationship between parent and child.

The first help is to make daily life livable for the child and its family. Psycho-education, day care centers and guesthouses are important tools in making daily life in families with a child with autism positive.

To summarize: Day centers should be established in every district with possibilities of receiving children for several days a week with the possibility of them staying overnight. Day centers should have the possibility of caring for children with ASD and also other special needs. In the day centers groups alternating with children together and apart (ASD and children with other special needs) would be indicated. The centers could function as a center for psycho-education of parents and families with children with ASD, and for professionals. Parents could be given a role in participation in the day center.

4: *Special education*

As far as the professionals involved in the FFM-A know, there only exists one autism unit in a special school in B&H. This is the autism unit of a special school in Tuzla that works together with the University of Tuzla. There is another unit, a group for preschool children with ASD, in a special school in Sarajevo. The special schools in B&H try to help children with ASD in their school, but are struggling with the idea of inclusion of children with ASD in regular schools. But the knowledge about ASD is rare, and the behavior of the children in a classroom is very inadequate. With regard to their very broad MAS1P within one child, one could say that most children with ASD are not mature enough for the regular school system. Their mental age with respect to school is more or less one to two years old, entering the first grade at six years and this mental age will remain at that level certainly with no treatment, during many grades. This is why children with ASD need one teacher per pupil, just like very young children. A child with ASD needs constant attention. But it is very difficult if you do not have enough knowledge about ASD to understand what is happening in your class room, and children are often excluded from school because the teachers do not know how to handle the children. In Banja Luka there is a Speech center. They do not have special facilities for children with ASD who, of course the severe form when they lack speech, come to this school.

One regular school in Sarajevo, Kovacici, admits many children with special needs, among them children with ASD. They have a director passionate for children with ASD and special needs in general. She worked as a school pedagogue with children with special needs before. This school works together with Duga, an organization in Sarajevo with much expertise on children with special needs.

The special school in Tuzla has an autism unit since 2005. The class room is nice with joyful colors, a mattress is available in a corner to enable children to retire and rest after therapy. In the autism unit are also other children with special needs. The education is very intensive. In the case of autism the ratio is more or less one teacher/one pupil. In one of the class rooms a small room has been constructed without a roof. The walls outside are painted with joyful images (see figure 6). Inside, the floor and the walls are covered with a thick layer of foam. The foam is covered with a kind of plastic, in a very dark brown color (see figure 7). In this room children can retire and come to themselves, if necessary with the aid of a teacher, or sometimes more teachers when it is very difficult to calm down a child. The color, dark brown, is somewhat amazing, because it is rather depressive instead of warm, calming down. The choice of this color was not the preference of the teachers. They wanted a more neutral, calming color. But parents insisted, and the teachers listened. The reason for parents was that the blood would not be visible when children hurt themselves. In this conversation about this room, the predicament parents and teachers are in becomes clear. Parents are often very desperate how to help their children, who can become very aggressive, particularly when they cannot speak. Children can hurt themselves, and parents do not want them to see that. Teachers feel a lack of knowledge how to help the children too, and lack training how to cope with difficult behavior of the children. As a result it is sometimes difficult for them to stand up for their expertise, and choose their own way. It is difficult too to help parents they know have to cope with the difficult behavior of the children all day long each day, and during all vacations.

Figure 6: *The room where children that are overly exited can retire to become calm again. The room has no roof, and no door. The entrance is at the side. The walls are painted with bright colors and joyful pictures.* *The photo shows the exterior of the room, that is situated in one of the class rooms.*	Figure 7: *The room is covered with thick foam on the walls and the ground and some mattresses. The floor, walls and mattresses are covered with plastic in a dark brown color. A mattress with a white cover and puppets on it, is also in the room.* *The photo shows the inside of the room.*

In schools, the participation of parents could become a positive contribution to teach the child, and to help the parents how to cope with the behavior of the child. Parents could be trained to help their children next to teachers, and part of the time train other children with ASD. It would alleviate the teachers task and cooperation with parents would help parents to work together, help each other, and broaden the care around the child. See further under 9: Training parents.
It is important to develop work possibilities for people with ASD. Job-coaching in order to help them how to find work, adapt to the demands are important subjects for the future help of these children.

To summarize: Children with ASD need special help in schools, very intensive help, one teacher/one pupil, certainly in the case of severe ASD. Throughout the country special schools with autism units are necessary. Parents should be trained to play a role in the school education of their child.

5: *Transport to school and day centers*

The country of B&H is beautiful, breathtaking, but it also is not easy to develop a good infrastructure in traffic. For the rural areas, it is not easy to reach facilities. There is nearly no organized school transport. This means that children depend on schools being in the vicinity of their homes. For children with autism, the situation is much more complicated, because there is a limited number of special schools, or schools with teachers who have some expertise on autism. For nearly all children with ASD this means that they are deprived from school. In the rural areas this also means that their parents can often not help them when they are analphabetic themselves. Special (school)buses or a network of people bringing the children to (a special) school is necessary.

To summarize: To reach school facilities a system of transport is necessary. School buses, or a system of parents working together to bring their children to school is needed.

6: ***Autism expertise centers***

There are no autism expertise centers in B&H. There are two centers developing for diagnose (see above: 1: diagnose), but it is limited to that. There are no expertise center where people can find information and training on subjects like treatment, school education, parent consultation, job coaching. An expertise centre would need facilities for training, treatment, observation, and also it would need to to train parents in helping their children to develop.

Duga in Sarajevo, already functions as an expertise center on children with special needs and trauma. Their mission statement already encompasses multidisciplinary team work. Perhaps it could develop a special department for autism.

The professionals in the different cities expressed a strong desire to establish an autism expertise center in B&H. Dzemil Vejzovic from Primanatura, Doboj, wants to establish an expertise center there. Doboj is situated in the north of B&H, not far from Tuzla and from Banja Luka. More autism expertise centers are necessary.

In the plan I developed for the universities, I propose to start a country wide expertise group of students, teachers and professors from different universities.

As stated above, probably scattered throughout the country, ex-professionals with expertise on autism exist. It would be good to try to find them and execute a kind of expertise ‘harvest’.

To summarize: There are no autism expertise centers. In the country five autism expertise centers are necessary. A group of specialists from different universities working together would be an important tool in developing expertise on a scientific base.

7: ***Parents Association***

In the case of autism, all over the world it are the parents who are the instigators to develop care and help for children and adults with ASD. The situation for parents often is so difficult, that they are desperate for help. One of the most important things for parents is to organize themselves as an association of parents with children with ASD. In B&H, parents with children with autism are beginning to organize themselves in Sarajevo (Ursad), Banja Luka (Siriko Brijeg), Tuzla (Urdosa).

Ursad, the Association of parents of children with ASD in Sarajevo is very active. They imported training from America for parents and professionals.

Of course parents want professionals to diagnose and treat their children, but the first thing for them is to cooperate together to help each other out in the daily problems they encounter. Helping each other out, and supporting each other is important. Certainly in the case of a small social inclusion in B&H.

To summarize: The parents association should develop country wide. There are important initiatives already in Sarajevo, Tuzla and Banja Luka. Parents could organize to help each other in the care of their children.

8: ***Training professionals***

Professionals need to be trained on what ASD exactly is, on diagnostics, and on what treatment methods are available. They need to be able to assist parents in the often difficult task of raising their child with ASD. For a better diagnostic system, specific professionals (psychologists and pedagogues together with social workers) should be trained to prepare an ASD diagnose and in order to do so be able to make the difference between ASD, QAP, trauma reaction, other developmental problems and other neurodevelopmental problems.

From the professionals in the autism unit of the special school working with the Tuzla University came the request to be trained in a *psychological approach* of children with autism. This as a result from the interactive lecture where the approach of children with ASD having severe aggression problems was discussed and an extremely difficult case was submitted (see 2:Treatment).

To summarize: B&H needs professionals throughout the country who know what autism is. There is a need for trained professionals who can prepare an ASD diagnose, professionals who know about treatment and can apply treatment, professionals who can help parents raise their child with autism, professionals that can be consulted when there is a problem, and professionals that can help schools concerning ASD. The professionals need training in the psychological approach of children. Also for adults. There also needs relation therapy for partners of whom one has an ASD.

9: *Training parents*

Parents have an intuitive knowledge that tells them there is something the matter with their child. But it is quite scaring and often exasperating to try to help their child with autism. As a result they cannot always reach their intuitive knowledge. Their extended family most of the time does not understand the behavior of the child either. It can make parents very insecure. They need help how to raise their child. They need help to assist raising their child, because you cannot do it by yourself. Autism comes along with a lot of anxiety in people with ASD and their families. Therefore parents need to have access to professionals with expertise on autism, to material that will help develop their child, but also access to training to help them develop the right attitude in communication with their child.

In the autism expertise center Ann Sullivan in Lima, Peru, parents and extended families are very successfully trained in some very important rules, all directed to respect and developing the full potential of growth of the child. The basic rules the parents learn in their behavior towards their child are: *Treat me with respect; Treat me like a human being; Listen to me; Do things with me; Expect something from me* (Delfos, 2004). A family school for training parents and extended families in raising the child with autism is an important element to make life in families with a child with ASD easier.

Parents can help each other with the daily care of their children. It would be a big help if parents succeed in organizing mutual help with their children.

To summarize: Parents need help to feel more secure, be trained to develop the right attitude in raising their child. Parents need to develop mutual help with each other on behalf of their children, to prevent a burn-out for themselves.

10: *Universities*

During the FFM-A three universities have been involved with respective key figures: in Sarajevo the International University of Sarajevo, IUS, with Professor Dr. Senija Tahirovic; in Tuzla the University of Tuzla with contact Mr.Sci. Selma Hodvic; in Banja Luka the University of Banja Luka with Assis.Prof. Dr. Nada Letic. In Sarajevo and Banja Luka, more professors were involved through the lectures and meetings.

All three universities expressed the strong desire to work with me together in research, especially on trauma and autism. To develop insight in war trauma in B&H, I developed a model on the Developmental Perspective in War Trauma (DPWT) (Delfos, in preparation). This model was received with enthusiasm, and the universities all expressed they want to develop this. Professionals expressed that they want it researched and developed as a tool to the way war trauma develops in

the post-war years. The reason for this is the importance of trauma in B&H and the contamination of autism and trauma with the risk of QAP (Quasi Autistic Patterns).
I developed a plan for a University Autism Expertise Group (UAEG) with students, teachers and professors with respect to teaching about ASD and research (data collection, diagnose, treatment, brain maturation, QAP, instrument development and validation) in B&H. This will be presented to universities in Sarajevo, Tuzla, Banja Luka and Mostar.

To summarize: Working together some universities could build a University Autism Expertise Group (UAEG) . Three universities (International University of Sarajevo, University of Tuzla, University of Banja Luka) are already very enthusiastic to work together on this. A plan has been developed and will be presented to the respective universities.

11: *Trauma expertise centers*

In B&H there are two expertise centers on trauma, Duga in Sarajevo and Vive Žene in Tuzla. They work already for many years in the field of trauma. They experience that the country seems to become reluctant towards being confronted with the consequences of war. Their knowledge could help empower people. Trauma expertise centers could play an important role in discerning (war)trauma from ASD, autistiform behavior from autism, QAP from ASD. The two centers expressed the desire to be involved in research in the field. Being a center on trauma help, does not mean that they reach everyone in B&H that would need help. The help, but also the knowledge about trauma has to be spread throughout the country. Not to victimize them, but on the contrary to empower people. They are interested in researching the model of Developmental Perspective on War Trauma (DPWT) (Delfos, in preparation) and want to develop it as a tool in diagnose and help in the case of trauma (see 10: universities).

To summarize: The trauma expertise centers have knowledge about trauma. They need to be involved in the research on DPWT, QAP and ASD, and are willing to do this.

12: Public awareness

The public awareness on ASD is very low, but the first articles in journals are being published. Awareness grows with information. All organization involved in autism help should be aware of the responsibility to contribute to the public awareness on ASD.

To summarize: The subject of public awareness on ASD is an important one. Developing help, and people connecting with each other on the subject is engendered by public awareness. All organizations that are involved should develop their contribution to public awareness. A country wide network should be developed and have a website where people can deposit their information and knowledge.

Cooperation possibilities with organizations in B&H

All organizations I met (see list below) expressed that they were very interested to develop their knowledge and skills in the field of autism. They feel that there exists a huge problem in B&H in this field, and they are in need of scientific and professional support.

The exchange at three universities (International University of Sarajevo; University of Tuzla, University of Banja Luka) with lectures for students and professionals resulted in the three universities asking me expressively to work together with me. As their request for developing expertise was very serious I developed an elaborate plan for building expertise in the universities. The wish to work together was sometimes already operationalized in squeezing a lecture or meeting with professionals from a center into the program. Another example is the wish to be trained in the psychological approach of children.
You can sense an enormous eagerness to learn, to develop research, to develop help and especially autism help. Some people said that it was exactly the right moment, B&H wants to rise from its ashes as a Phoenix.

Organizations involved in the FFM-A in B&H
The following organizations were involved in the week FFM-A in B&H. All organizations have expressed their wish to work together in general and in the project of autism in particular.

Centar Vladimir Nazor, Special school 1, Sarajevo
Clinic of Child Diseases, Child Neurology department, Banja Luka
CNFCEE, Cooperating Netherlands Foundations for Central and Eastern Europe, Banja Luka
Duga, Tuzla
Hospital, Neuro-Psychiatric Ward, autism diagnose unit, Sarajevo
International University of Sarajevo, Sarajevo
Kovacici , regular school, Sarajevo
Primanatura/ Holland Hart Huis, Doboj
Psychiatric Hospital, Child Psychiatric Ward, autism diagnose unit, Banja Luka
Sign, Gender and Diversity, Sarajevo
Social Service, Doboj
Special school 2 , Sarajevo
Special school, autism unit, Tuzla
Speech center, Banja Luka
University of Banja Luka, Banja Luka
University of Tuzla, Tuzla
Urdas, Association of parents, Sarajevo, Tuzla, Banja Luka
Vive Žene, Center for Therapy and Rehabilitation, Tuzla

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About the author

Prof. Dr. Martine F. Delfos studied clinical research psychology in the late sixties and French language and literature (cum laude) in the early nineties at the University of Utrecht, The Netherlands. In 1999 she obtained a (double) doctorate (with a psychological and literary research about how French writers cope with death (Editions Rodopi, Amsterdam). She is professor on *Virtual environment of the youth* at the Professional University of Hengelo, The Netherlands.
Since 1975 she has been working as a psychologist/therapist/diagnostician. She has a broad scientific specialization field encompassing autism; multiply traumatized children, adolescents and adults; sexual abuse; aggression disorders; and eating disorders. Her scientific expertise is especially the construction of bio-psychological models on human behavior. She constructed among others a model on autism, and one on anxiety and aggression disorders with practical application.
She works, among other things, within youth care and provides post-graduate courses for psychologists, remedial educationalists, physicians, social workers and group leaders. She gives lectures in The Netherlands and abroad.
In 1997 she founded the PICOWO/PICES: Psychological Institute for Consultation, Education and Scientific research, and is involved in research in The Netherlands and abroad.
In addition to her work as independent therapist and lecturer she has been publishing books: since 1993 therapeutic children books, and books in the field of psychology since 1996.
Apart from the publication of various articles, she wrote several handbooks used in universities and professional education. Handbooks on autism, developmental psychology, psychopathology, communication with children, and gender. Her books are being translated in English, French, German, Spanish and Burmese.
Information on the website: www.mdelfos.nl

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And I do hope this FFM-A will be the start of a contribution to the people of B&H to help them develop autism help in their country.

Prof. Dr. Martine F. Delfos
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