



It's a strange world

Update October 2010
Report 04 of the endeavor to develop
Autism and Trauma Help in Bosnia and Herzegovina



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Introduction

This is the fourth report on the development of Autism Help in Bosnia and Herzegovina (B&H). The first three reports were the result of the Fact Finding Mission in Bosnia and Herzegovina in May 2010. The first report (FFM-A report-01, Fact Finding Mission Autism) is the result of the findings of my visit to B&H in May 2010, available on website www.mdelfos.nl/BiH.htm, where all the reports will be accessible. In this report the situation of B&H in general and specifically with respect to autism is described. The second report (UAEG-plan-report-02, Universities Autism Expertise Group) is the plan how to start an expertise group on autism in B&H, also available on website www.mdelfos.nl/BiH.htm. In fact this expertise group already started off during the Fact Finding Mission in May as a result of the exchange with the universities and expertise centers. The third report, about a conference, is not yet available for public. An article has been written on the Trauma model I developed and its application on the war trauma in B&H (DPWT, Developmental Perspective on War Trauma), not available for public yet.

This fourth report is an update resulting from the visit in October 2010 in B&H.

Between May and October 2010

During my visit in May 2010 many contacts were made. I was grateful for all the cooperation that made it possible to give me an insight in the situation of B&H, and describe the situation with respect to autism. But it was more than that. In many situations cooperation already started off during that week, which resulted in the plan I developed on the UAEG (report 02). Between May and October 2010 (the date of my second visit to B&H), email exchange between my contacts in B&H and me were developing in a steady way. As a result the UAEG was beginning to develop already. Preparations were made to make the visit in October as fertile as possible. Unluckily the funding was not complete when I went to B&H, but I did not want to let people down. The organization Protestants Christelijke Vereniging voor Jeugd- en Kinderzorg, in the person of Rick van der Ploeg funded the travel expenses, some of the interpreter costs, and the costs of the assistance of a fundraiser, Bert van der Linde, to enable him to join me for some days to investigate possible funding for the project.

From Selma Hodzic-Mesanovic (*Institute for the education of children with difficulties in psychological and physical development Tuzla*) came the request to come back and give a training on the 'Psychological Approach of children' This was a reaction to my work with professionals on communication with children in May 2010. The International University of Sarajevo continued on the idea of the UAEG and selected four students to participate in the UAEG. My visit coincided with the start of the academic year and the students were ready for action. From the university of Banja Luka Nada Letic (*University of Banja Luka/ Child Psychiatric Ward/Clinic of Child Diseases, Neurological Department*) followed up the idea on the necessity to unravel trauma and autism in the diagnose of autism. She collected eeg-material of the diagnoses on autism from the Clinic of Child Diseases, Child Neurology department in Banja Luka.

Before my second trip, I met people from Microsoft The Netherlands and there was a keen interest to help people in B&H develop a virtual environment like I proposed in the UAEG-plan-report-02. In the meantime they gave me the contact person of Microsoft in B&H.

As fundraising is not my field, people from The Netherlands expressed they would like to help me raise funding. Especially Marian Rameyer from Kontakt der Kontinenten and Bert van der Linde, same organization, living in Croatia since fifteen years.

Sir Michael Rutter, the distinguished professor of Child Psychiatry from England, showed a keen interest in my reports, and made clear that no research has yet been initiated on his idea of *Quasi Autistic Pattern*, and he is very positive about research endeavors with respect to this subject. And even more activities went on as a result of my FFM-A, which I discovered with joy during my visit in October.



Activities during the visit in October 2010

From 18 till 27 October 2010 I paid my second visit to B&H. For a short overview of my activities during this visit see the table below.

Table 1: Activities Autism and Trauma Help in B&H, 18-27 October 2010

Day	City	Organization	Name and function	Lecture/meeting
Monday	Sarajevo	International University Sarajevo, IUS, FASS, Faculty of Arts and Social Sciences	Ass.Prof. Dr. Senija Tahirovic Child psychologist and Coordinator Psychology Programm + practioner	meeting
			Assoc.Prof. Dr. Ali Gunesş Dean FASS	meeting
			Enes Pivic, Director IT; Zinka Bejtlic, Coordinator and teacher Visual arts	meeting
Tuesday	Mostar	University of Mostar Faculty for teachers, Department of Psychology	Prof.Dr. Pezo Salko Dean; Dr.Jasmina Sose, Head of Department Psychology; Vesna Corluka, Senior Assistant.	meeting
			Students and teachers	Lecture on autism
		Los Rosales Special school and expertise center	Director Jasna Rebac	Meeting, and visit Los Rosales
Wednesday	Tuzla	University of Tuzla Faculty of Education and Rehabilitation; Faculty of Psychology	Ass.Prof.Dr. Fata Ibralic, associate professor Vice Dean for the science and research; Dr.Sci. Amela Ibrahimagic Ass. Prof. Speech and language pathologist; Mr. Sci. Dr. Selma Hodzic-Mesanovic, Pedagogue; Ass. Prof. Dr. Alma Dizdarevic, Department of Education and Rehabilitation of the Faculty of Education and Rehabilitation.	meeting
			Special school Institute for the education of children with difficulties in psychological and physical development	Mr. Sci. Dr. Selma Hodzic, Pedagogue; Damir Muratovic School pedagogue autism unit; Director Sanela Mandzukic
		Parents of children with autism + staff special school	Meeting + visit school	
Thursday	Tuzla	University of Tuzla, Faculty of Education and Rehabilitation; Faculty of Psychology	Students, teachers, parents of children with special needs	Training, first of two days on the Psychological Approach of children.
			Children and adolescents with autism (+ staff)	Diagnostic and treatment interviews
			Parents of children, and children with autism (+ staff)	Diagnostic and treatment interviews
Friday	Tuzla	University of Tuzla, Faculty of Education and Rehabilitation; Faculty of Psychology	Students, teachers (Universities Tuzla and Sarajevo), parents of children with special needs	Training, second of two days on the Psychological Approach of children.
		Special school,	Parents of children with autism	Diagnostic and

		<i>Institute for the education of children with difficulties in psychological and physical development</i>		treatment interviews
			Children and adolescents with autism + staff	Diagnostic and treatment interviews
Saturday	Doboj	Primanatura, Holland Hart Huis	Dzemil Vejzovic, Director Primanatura and Holland Hart House.	meeting
			Parents of children with autism + staff	Diagnostic and treatment interviews
Sunday	Banja Luka	University of Banja Luka + CNFCEE	Ass.Prof. Dr. Nada Letic (University of Banja Luka/ Child Psychiatric Ward/Clinic of Child Diseases, Neurological Department); Branka Ivanovic, Coordinator CNFCEE.	meeting
Monday	Banja Luka	University of Banja Luka <i>Faculty of Philosophy, Department of Psychology</i> University of East-Sarajevo in Pale	Milena Pašić, Psychologist, Head of the Department of Psychology; Prof. Petar Stojakovic, Educational Psychology; Ass.Prof. Dr. Nada Letic; Prof. Spasenija Čeranić Clinical cases at the Department of Psychology the University of East Sarajevo in Pale	meeting
			Students and teachers + expertise centers	Lectures on communication and the virtual environment
		Psychiatric Ward of Banja Luka	Mira Spremo + staff	Lecture on autism
Tuesday	Doboj	Primanatura, Holland Hart Huis and Medical Center Doboj	Professionals + teachers + parents	Training/workshop on sexual education
			Parents of children with special needs	Continuation of diagnostic and treatment interviews with parents from the meeting on Saturday before in Doboj.
Wednesday	Sarajevo	International University of Sarajevo, IUS, <i>FASS, Faculty of Arts and Social Sciences</i>	Assoc.Prof.Dr. Ali Güneş Dean FASS	meeting
			Students of the UAEG and	meeting
			Students, teachers, expertise center	Lecture on autism, communication and virtual environment
		Duga Expertise center	Marina Nezirovic, project coordinator	Brief meeting
		Child therapy practice	Prof. Dr. Senija Tahirovic	Meeting + visit Child Therapy Practice

Update from the visit in October 2010

The visit in October showed me how much already had been established during my visit in May the same year. People were very eager to do something in the field of autism, very happy to work with me, and initiated and followed up several projects on subjects that were addressed during the Fact

Finding Mission. People were satisfied with the reports. The first report FFM-A will be used as a bottom paper for the NGO Primanatura in Doboj. The cooperation between Primanatura and Picowo to establish an Autism Expertise Treatment Center in Doboj has been agreed upon.

The plan described in report-03, not available for public yet, is progressing nicely, and important contacts have been made, to try to realize it.

During that week in May it became clear that three universities would be interested in working together with me and with each other. I wrote the UAEG-plan, and the people involved in the FFM-A received this. There was almost no comment on the content of both reports, so we had two bottom papers everyone agreed upon as a general idea.

Universities

Before and during my visit in October two new universities (Mostar and Pale) expressed the intention to join the UAEG, to add up to five universities at this moment. I am extremely proud that these five universities represent the three important ethnic sources of the country: Bosniacs, Serbs and Croats; and the three religions: Muslim, Orthodox, Catholic; and many more people. Why I am so proud is that these religions or ethnicities were not noticeable. I only met people dedicated to help children and adults who have trouble getting the help they need. There was no one speaking about ethnicities or religion. Not hiding it either; it was not the focus. People want to connect to people; it is not different in Bosnia and Herzegovina than anywhere else. The five universities intend to work together as a Bosnian Expertise Group. For the participants see table 2 below.

Table 2: Universities participating in the UAEG

City	University	Status of cooperation	UAEG key professional	Students
Sarajevo	International University of Sarajevo	Cooperation succeeded	Ass.Prof.Dr. Senija Tahirovic	Four students recruited
Banja Luka	University of Banja Luka	Cooperation in full progress	Ass.Prof.Dr. Nada Letic	Students being recruited
Mostar	University of Mostar	Cooperation started	Dr. Jasmina Sose	Students being recruited
Tuzla	University of Tuzla	Cooperation in full progress	Ass.Prof.Dr. Amela Ibrahimagic	Students being recruited
Pale	University of East Sarajevo	Cooperation in preparation	Prof. Spasenija Ćeranić	Preparation of students being recruited

To help me belong to the UAEG, two universities offered to appoint me as visiting professor. In May already the dean of the FASS, Faculty of Arts and Social Sciences of the International University of Sarajevo asked me if I would be willing to become a professor at their university. This visit in October we agreed I would be appointed visiting professor from then on. The University of Banja Luka also proposed this possibility so that I would belong to their university too. I am very happy with this, because I will need to belong in some way to the organization and people in B&H to be able to truly work together.

Students

In the *International University of Sarajevo*, already four students have joined the UAEG: Ersan Simsek, Sumeyye Akkoyun, Emina Bejic, Bozena Bilic. They attended the lecture in May, the two-day training in Tuzla October and the lecture in Sarajevo in October. We had a meeting to speak about the UAEG. They will read the reports, think about which research and adoption project they want to join, and will discuss this with Ass.Prof. Senija Tahirovic, who will discuss this with me.

In the *University of Tuzla* many students attended the two-day training. They were told about the UAEG and were asked to think about it and let Ass.Prof. Amela Ibrahimagic know if they want to join the expertise group.

In the *University of Banja Luka* also many students attended the lecture. Ass.Prof. Nada Letic is recruiting the students who could join the UAEG.

In the *University of Mostar* many students attended the lecture. They were told about the UAEG and were asked to think about it and let Dr. Jasmina Sose know if they want to join. One student already applied to join the UAEG.

The *University of East Sarajevo* is starting up the cooperation. Prof. Spasenija Čeranić also attended the lecture at the University of Banja Luka.

The digital environment

At the University of Sarajevo I met the key professionals of the IT, digital environment, Enes Pivic (IT) and Zinka Bejtic (Visual arts). We had an interesting meeting and Enes Pivic showed me the equipment of the IUS. He said that he was able to do the hosting and webmastering of a website on autism for B&H, in a secure environment. He was also more than interested in working together in developing a virtual environment as proposed in the UAEG-plan-report02. Zinka Bejtic from the department of Visual Arts said that she was prepared to develop a website on autism for the UAEG. Both expressed the desire to work together with all five universities.

We agreed that this could be a proposal for all the universities working together in the UAEG, and that I would write a report (which would be Virtual UAEG-report-05) to have a paper participants could think about. In the meantime I made contact with the Breda University of Applied Sciences in The Netherlands. They have an extensive, and unique, curriculum for constructing games and developing virtual environments. I discussed the virtual environment I proposed in the UAEG-plan-report-02, and it was met with appreciation and enthusiasm (Frank Zijlmans). They are interested in working together with B&H in order to develop the virtual environments I proposed. They will look at the report (on the construction of the website (Virtual UAEG-report-05) and the virtual environment).

Professionals

During my visits in May and October I met many professionals and I am honored to be able to work with them. We exchanged ideas, and together we feel we are able to form a platform on which autism help and trauma help could be developed. We discovered that much of what we spoke about also applies to children with special needs, and that the boundaries should not be set too sharply, certainly at the beginning.

I met many very warm, intelligent, and strongly motivated women and men in universities, special schools and expertise centers. With two of them I discussed the outline of a book they are writing. Prof. Dr. Senija Tahirovic is writing a book on Child Psychology and Ass.Prof.Dr. Nada Letic a book on Child Psychopathology. As a result of their work, I trust there will be highly qualified textbooks in B&H.

Expertise centers and organizations

Several expertise centers were involved in the visit in May and in October. The expertise center Duga in Sarajevo expressed the desire to work together and to possibly function as an NGO to help fundraising for the plans expressed in the two first reports: the FFM-A and the UAEG-plan. Several special schools could be interested to join the UAEG, and will be invited, some of them already expressed the desire to join the group. In October I visited Los Rosales in Mostar, an expertise center that values parent participation which could be an important contribution to the UAEG.

The ideas discussed during the visit in May about the parents of children with autism organizations have been taken up successfully since.

Vive Zene did not join the UAEG yet, because he group is focused on autism, whereas their focus is trauma. They showed a keen interest in the DPWT (Developmental Perspective on war Trauma) though, and will be invited to share participation in that field.

The DPWT-model has caused a lot of interest, it seems to prove helpful in understanding behavior of children as a result of war and of parents who were adolescents during the war and are young parents now. Branka Ivanovic expressed the desire to stimulate research on this model. In The Netherlands too, Laura Roos, expressed that she is interested in Phd research on the trauma aspect, DPWT/QAP (Developmental Perspective on War Trauma / Quasi Autistic Pattern).

Research

In May I discussed the problem of a possible tsunami of misdiagnoses in B&H as a result of trauma instead of autism. This because autism is still diagnosed on behavioral symptoms, and some of the same symptoms could arise from trauma. Ass.Prof.Dr. Nada Letic took this problem seriously and tried to examine the diagnoses already performed from the perspective I described. Also my stressing maturation led the psychologist and the neurologist of the Child Disease Clinic, to examine the eeg from the autism diagnoses with respect to maturation. This seems to lead to interesting findings as far as it presents itself now.

The stimulation of parents of children with autism to connect to each other and develop solutions in the daily worries parents with those children also has started.

Working with children and adolescents

During this visit in October, I was given many opportunities to work with children and adolescents, especially in Tuzla and Dobo. Of course this is what it is all about, so it is the most gratifying to do, to work with the children and adolescents. Sometimes it was together with their parents.

There were several things that impressed me. First the many children who did not show any sign of autism before 2 ½ till 4 years old, and then showing severe autism within a very short time. It is possibly the expression of a kind of trauma, or situation experienced as traumatic by the child, an expression of QAP, and Nada Letic from Banja Luka told me there are many children like that diagnosed with ASD.

The second thing that impressed me, is that some children were suffering from parenting because parents were reluctant in setting the boundaries. It is a problem one can see in most countries in the world, and certainly in the rich ones. Parents can offer their child almost anything they want, but they seem reluctant to suffer the disapproval from children when these parents set boundaries.

And third, most important, many children with no or little speech suffered from the lack of communication by their parents and carers, which made them anxious or aggressive. I phrased it like this: *When children shut up, parents shut up.* Parents of non-speaking children, and carers tend not



to explain what happens to children who do not speak. This is quite a gap in knowledge children with autism lack because of their parents becoming silent like them.

Perhaps I will write about my experiences in working with parents and children in another report, that would be report 06: Working with children and parents.

Where do we go from here?

In two short visits it became crystal clear that people in B&H are very motivated to develop autism help, and that they are willing to do this together, with me helping them. In November there was a very painful article in a newspaper about a desperate mother who stabbed herself, because she did not get the help her five year old child with autism needs.

As I used an existing infrastructure, the universities, immediately all kind of initiatives could be started. The country lacks the financial possibilities to really develop such help and do the research projected, but they try to do what they can.

It would probably be wise to establish an NGO in B&H with the participation of the universities, expertise centers and parent organizations, to have an infrastructure that is capable of establishing autism help in B&H as projected in the first two plans. This way it could exist on its own, and from the country itself. My role would be to simulate, help and support the endeavor, so that the people of B&H can develop the autism help and at the same time precise trauma consequences in children and parents themselves more precisely. I do not intend to become a director of such an NGO, to be clear about this from the beginning. My role would be purely directed to supporting on the content level, not on the management level. I would need a Bosnian assistant though, and I know one who can express herself in English and Dutch, and who is fully aware of the psychological issues, Tiana Kulenovic. Interpreters are necessary too.

The infrastructure of the universities can be used, but financially they do not have the full power to support such an endeavor as the FFM-A and UAEG, but its infrastructure will already be quite an asset for an NGO *Autism and Trauma in B&H*.

Thanks! Hvala!

There are many people I have to thank, and would like to thank, I cannot insert all their names here. Of some of them, I do not even know their name.

I enjoyed enormously to meet again and meet for the first time: Senija, Selma, Nada, Mira, Amela, Alma, Petar, Branka, Damir, Ivana, and many many people I cannot name all here. I loved meeting my students and having breakfast with them in Tuzla. I enjoyed so much working at the universities. I thank the parents to share their worries with me, and show me time and again the love of parents for their child in need. But most of all I thank the children and youngsters who let me into their lives, forgiving me my incapacity to speak Bosnian, speaking English with them, and joining them in their non-verbal language. Because it is for them that I engage in this immense project.

Martine Delfos

12-12-2010, Utrecht, The Netherlands

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. She has been appointed Visiting Professor at The International University of Sarajevo in Sarajevo, Bosnia and Herzegovina.

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; relation therapy; 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, one on anxiety and aggression disorders, and the encompassing model on sex differences and similarities of men and women.

She works, among other things, within youth care and provides pre- and post-graduate courses for psychologists, remedial educationalists, physicians, social workers, and group leaders, 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 many articles, she wrote several handbooks used in universities and professional education in The Netherlands and abroad. Delfos wrote handbooks, among others, on autism, developmental psychology, psychopathology, communication with children, and gender. Her books are being translated in English, French, German, Spanish, and Burmese, and Bosnian translations of some books are being prepared.

Information on the website: www.mdelfos.nl