It's a strange world

Universities Autism Expertise Group – UAEG

Autism in Bosnia and Herzegovina

Prof. Dr. Martine F. Delfos

Contents

Introduction

In this report a plan is presented to develop a *Universities Autism Expertise Group* (UAEG) in Bosnia and Herzegovina (B&H). In May 2010 I did a Fact Finding Mission on Autism (FFM-A) in B&H. During the week I was there, I visited many institutions, and met many people. There was an exchange of information, and lectures were given at universities and expertise centers.

Three universities have been involved in the FFM-A, 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 M.Sc. Dr. Selma Hodvic; in Banja Luka the *University of Banja Luka* with Assis. Prof. Dr. Nada Letic.

I use the term autism and ASD (*Autistic Spectrum Disorders*) interchangeably, in line with the new DSM-V and the ICD-11 (both classification manuals on mental disorders, see References: APA and WHO) expected in 2012/2013.

Autism: the core of the matter

[This paragraph is taken from the FFM-A (Delfos, 2010)].

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 that 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 within 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 years in mathematics and 35 years 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 & 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 in ASD, which complicates the situation of the child/adult and the family enormously.

For further information on autism in B&H and the ideas on developing autism help in B&H I refer to the report of the Fact Finding Mission-Autism (FFM-A) (Delfos, 2010).

The need for an expertise group for developing ASD help in B&H

Much information was yielded during the FFM-A, though information on autism care was very limited, because help and care in the field of autism are 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 for autism help. 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.
As knowledge about autism is very scarce, it is a first necessity to gather knowledge and spread this throughout the country. An expertise group is necessary to ensure the right knowledge, founded in research.

Conditions for an expertise group

The necessity to build autism help in B&H became very clear. To build autism help in a country you need to empower the country to develop it themselves. You need to embed help in existing structures. The most important one is the structure of universities. Here knowledge is shared with the whole world, access to knowledge throughout the world has existing infrastructures in universities, and developing knowledge itself is the very pulsing heart of the university. Universities have the very structure in order to build something that has growth power, has possibilities to survive by itself in independent thinking, the capacity to grow by itself, and universities will exist notwithstanding the circumstances.

One can formulate some characteristics which such an expertise group should satisfy:
1: A group working together
2: Country-wide
3: Universities
4: Youth
5: Embedded in a system that will pursue form itself, like a curriculum in universities
6: Working relationships with expertise centers
7: Accessibility throughout the country

The structure of the expertise group

The best choice seems to be to form a group with people from universities. The Universities Autism Expertise Group (UAEG) intends to form a task force to implement autism knowledge in B&H. Three universities (Sarajevo, Tuzla, Banja Luka) already expressed the desire to work together in the field of autism during my FFM-A, and in the weeks following my journey to B&H. A fourth university in Mostar would be very welcome to join the group. Professor Tahirovic of the International University of Sarajevo expressed the possibility to contact the University of Mostar to invite them to join the three universities that already expressed the desire to work together.
The core participants of the group should be students (psychology/pedagogy/defectology) surrounded by their teachers and professors. The youth has the future, as the saying goes, so these

students would be the future of autism help in B&H. One aspect about young people in B&H is that they will connect more easily, probably less affected by the fear that was engendered by the war (see FFM-A, Delfos, 2010).

To form a substantial and at the same time workable group, three students (psychology/ pedagogy/ defectology) per university should be invited to take place in the UAEG. They would have to be enrolled in their second or third year in the season 2010-2011. This would mean that two years of expertise development could take place within the universities. Two female students and one male if possible. The students would have to be selected according to the following criteria: 1 good students, 2 choose to specialize in autism during their study (minor autism, to follow extra modules on autism, fieldwork in the field of autism), 3 with a personal interest in the field (having a person with autism in the family, or knowing a person with autism, or autism traits, or some very specific motivation for the field of autism). This would result in a group of 9/12 bachelors specialized in ASD within two years.
In each university there needs to be a key figure to coordinate the courses and the autism research:
Sarajevo: the *International University of Sarajevo, IUS*, with Professor Dr. Senija Tahirovic;
Tuzla: the *University of Tuzla* with contact M.Sc. Dr. Selma Hodvic;
Banja Luka: the *University of Banja Luka* with Assis. Prof. Dr. Nada Letic.
Mostar: not yet known
Each university that is working with the UAEG will give courses in ASD, and develop a minor. The students participate in research from the UAEG, and each student adopts a specific field of interest (see further on: Students Adoption Subjects)

In the introduction some conditions for an expertise group were made explicit:
1: A group working together
2: Country-wide
3: Universities
4: Youth
5: Embedded in a system that will pursue form itself, like a curriculum in universities
6: Working relationships with expertise centers
7: Accessibility throughout the country

With such a group as the UAEG, the conditions 1 to 5 are met.
Most likely some of them will follow a master after the bachelor and will remain in the group if the subject of internship is related to ASD. Some of them will be interested to follow up the education by a PhD., they also would stay in the group if the subject of the PhD is related to ASD.
The universities build expertise on autism, give courses in autism, develop a minor in autism, and do research on autism.

The sixth condition (Working relationships with expertise centers) could be met when the UAEG takes up the responsibility to work together with expertise centers throughout the country. As some expertise centers (Duga, Vive Žene) already expressed the desire to work together during the FFM-A, this seems to be possible.
The seventh condition is not so easily met. The infrastructure of the country is scattered, and conditions, even for transport, are not always easy (see FFM-A, Delfos, 2010). As the world is changing rapidly into globalization with the pace of internet, the new possibilities should be used to solve problems. Therefore the virtual environment could be helpful.

Accessibility: Virtual environment

As to accessibility two points are of interest:
1: How to enable regular meetings from members of the UAEG.
2: How to make the knowledge gathered accessible throughout the country.

Arranging meetings on a weekly basis with a group that is so spread throughout the country is not possible. However, the virtual environment offers a possibility to meet on a daily basis. The physical conditions to develop an infrastructure are available in universities: internet and computers.
This is not to be the only meeting place, nor the most important. Real Life contact is always the most important way to have contact with each other. The virtual environment is only to enable quick exchange and overcome the travel problems with a group that works throughout the country.
For the UAEG to communicate easily with each other a virtual meeting platform should be developed. Here also, the universities are the most indicated infrastructure to use to develop this.

Students from the ICT (Information and Communication Technology) faculty could be brought together to construct a website and a virtual environment for the UAEG. Two students (ICT faculty) from each university mentioned above (6 to 8 students), enrolled in their second or third year in season 2010-2011. They would have to be interested in developing a website for the UAEG, and to begin constructing a virtual world for the UAEG. These students would have professors in their faculty to help them with their construction work in the virtual environment. A working relation abroad would be indicated, for instance with the professional University in Breda, The Netherlands, where they teach the construction of games and virtual worlds. Incidentally Universities like Harvard University or the University of Utrecht use the virtual environment of World of Warcraft to meet, have workgroups with students, and lectures.
The first result of this ICT-group would be a website, where everyone - parents teachers, experts in the field - can find information on ASD and related to ASD.
The second result would be the *Autism Expertise Virtual Environment*, where students, teachers/professors and professionals from the UAEG can have meetings. In this virtual world there would be a library with material on autism and related subjects, a research lab, where the beginnings of a diagnose could be effectuated. A 'diagnose-kit' consisting of a computer, internet connection and webcam could be used by professionals in the field (psychologists, pedagogues, defectologists) to provide film observation material through a safe internet connection for specialists in diagnose and treatment living far away from the specific family and child.

For the accessibility throughout the country the developed website and the Autism Expertise Virtual Environment are solutions (condition 7). The virtual environment could be a starting point for exchange on autism. Of course it could never take the place of Real Life Contact, but it can be helpful in finding expertise and as a starting point to find people in the field to meet.

Research subjects

From the FFM-A in B&H, from my personal expertise on autism, and from contact with professionals after the FFM-A, there are already several research projects that present themselves from the gathering of information during the FFM-A in may 2010. They are discussed in a brief way in 10 points below. The list is not exhaustive, but a starting point to work on developing autism expertise in B&H. For some of the subjects working together with universities abroad is indicated.

1: Diagnose, data collection

There needs to be a data collection on children, adolescents and adults with ASD. Policy as to help and developing institutions in the field of ASD needs an insight in prevalence and coverage of education, diagnose and treatment. Research on data collection in diagnostic centers, with pediatricians, psychiatric wards in Banja Luka and Sarajevo is also needed. Number of diagnoses a year; diagnose according DSM-IV/ICD-10.

[The rest of this point 1: Diagnose, data collection is taken from the FFM-A (Delfos, 2010)].
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 1, the statistical translation of prevalence of autism according to the real and an estimated population count is shown. 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 1: *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.*

2: Diagnose, instruments

Several instruments to enable diagnose should be developed, translated and validated for the B&H situation, to begin with the ADOS, QAP and DWTP.

ADOS
Observation is one of the most important tools in diagnose of ASD. As the ADOS (*Autism Diagnostic Observation Scale Schedule*, Lord et al., 2001) came out positively in research on early detection (Servatius-Oosterling, 2010) a two-way translation of this instrument (Koller et al., 2007) in Bosnian and validation of this instrument in B&H is warranted.

QAP
It is not always easy to discern ASD from other disorders or problems. The Romanian 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*. Proffessor 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. Construction and validation of an instrument discerning between ASD and QAP is important. Certainly to prevent a 'tsunami' of diagnose when autism comes into public awareness in the country, as became clear in other countries.
There yet exists no instrument to diagnose QAP and there is a need for such a tool (Michael Rutter, personal communication). Rutter developed criteria that could be very useful. 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. Working together with the trauma expertise centers is warranted.

DPWT
In order to better understand the effect of war trauma in B&H and the effect on children, I developed a model on the *Developmental Perspective of War Trauma* (DPWT, Delfos, in preparation). This model was received with enthusiasm in the three universities, and they all expressed wanting to develop this model into a tool in diagnose. Professionals expressed that they want it researched and developed as a tool to the way war trauma develops in the post-war years. It could prove useful in discerning between trauma and other problems, and also discerning from ASD.

MAS1P
The complexity of autism/ASD comes from the fact that it comes along with a broad *Mental Age Spectrum within 1 Person* (MAS1P, Delfos, 2005). In order to make a diagnose comprehensible for treatment, one should be able to describe the different mental ages for different subjects, develop a chart of mental ages to be applied in diagnose for each individual with autism. The Čuturić, a developmental test validated for a B&H population, could perhaps be helpful to develop this.

3: Diagnose, parents intuition
Parents have an intuitive knowledge that tells them there is something the matter with their child. In the research on early detection (Servatius-Oosterling, 2010), the early detection by professionals never reaches the level of parents themselves. Parents are very good early detectors, in fact they knew it was in the genes long before research on genes made clear that ASD is mainly a genetic disorder. The problem, however, is that parents have trouble communicating with professionals

about their own expertise. In Ecuador, research is going on to discover how parents 'diagnose' and how to use the knowledge (Groot & Delfos, in preparation). Research directed at eliciting parents' knowledge and translating it into professional expertise would help enormously to develop early detection. Research on intuition is becoming an important focus of attention in the scientific world.

4: Diagnosis, developing a pre-diagnose team

As the prevalence of ASD is quite high, B&H awaits a large increase of diagnose requests on ASD in the coming years. In many countries waiting lists are developing, and as a result, diagnose cannot always be established conforming the rules, that is by multidisciplinary teams (psychiatrist, neurologist, psychologist, pedagogue, social worker).

It would be advisable to train child psychologists and special pedagogues in preparing a request for an ASD diagnose. Universities could work to develop a model of pre-test. The model should incorporate what the first signals for (early) detection are, what tools could be used in the pre-test situation, and what qualities and knowledge professionals need to have to be able to prepare the diagnose in a multidisciplinary team.

5: Diagnose, diagnose of adults

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. Research should be directed at following the general development and translating and validating instruments used in diagnosis of adults.

6: Maturation of the brain

In the DSM-V and ICD-11 autism will be classified as ASD without all the different forms, except Rhett disorder and Desintegrative disorder of childhood. It will be classified under cluster 2, Neurodevelopmental disorders, that is characterized by an atypical maturation of the brain (Swedo, 2009).

The Clinic of Child Diseases in Banja Luka does EEG measurements as a standard procedure in diagnose of ASD 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 give an indication of the *maturation* of the brain, which will probably be one of the biological markers in the future, and as such an important subject for research.

7: Expertise 'harvest'

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. An expertise 'harvest' to find the expertise still existing somewhere in B&H still seems to be called for and sensible. A methodology to discover the expertise should be developed.

8: Education

The educational needs of children with ASD are not well understood in B&H. Teachers and parents are looking for help in this field. Research could help to point out the special needs of children with ASD.

9: Treatment

There is no cure for ASD, and treatment for helping children with ASD is still in progress of development in the world. ASD is a very complex disorder. So, once a diagnose, the treatment is not obvious. There is no medication that helps in the case of ASD, only for side effects like epilepsy. The core of the matter (MAS1P) should be addressed. Because of the many problems with children with ASD, certainly those who do not speak, or nearly not, parents and teachers resort to repression.

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.

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). It is helpful, but it does not really address the core problem. 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 with 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, Besems & Van Vugt, 2008) works with developing the person with ASD from the perspective of a lack of maturation and the aim is to stimulate this maturation.

Research on treatment methods for ASD is important.

10: Training parents

Raising a child with autism is quite a challenge. Developing mutual help for parents could be very helpful in the daily stress of raising a child with ASD. Research could help Parents Associations to develop a model of mutual help of parents with families where they have to raise a child with ASD.

Another subject is training parents in coping with the behavior of their child and how to communicate with their child, even when the child does not speak.

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. Research could help develop a training program for parents.

Students Adoption subjects

Students from the UAEG could choose a subject to adopt. As a result, each student would be responsible for one subject by deepen knowledge about it during two years, by keeping an eye on the development of the subject, by acquiring information about it. Some subjects could be:

1: To follow the development of DSM-IV to V, and ICD-10 to 11 with respect to ASD.
2: To effectuate a two-way translation of the ADOS.
3: To provide material for an ASD website.
4: To follow the development of Associations of Parent with children with autism.
5: To make a compilation of treatments.
6: To keep contact with research in Ecuador.
7: To make a Newsletter for the UAEG.
8: To keep an eye on the development of adults diagnose in the world.

Synthesis on autism expertise development group

In table 2 the synthesis model of the development of a Universities Autism Expert Group, UAEG for B&H is presented.

UAEG Universities Autism Expertise Group	Virtual Environment *Website* *Autism Expertise Virtual Environment*
Faculties: Psychology, Pedagogy, Defectology 3 or 4 universities 3 students per university 2 female, 1 male Teachers and professors Professionals expertise centers Research programs Minor autism Students Adoption Subjects	Faculty: ICT- Information and Communication Technology 3 or 4 universities 2 students per university Teachers and professors

Table 2: Schematic reproduction of the development of an autism expertise group

Prof. Dr. Martine F. Delfos
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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. Delfos wrote 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