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## PARENTS' PARTICIPATION IN THE SOCIAL INCLUSION OF CHILDREN WITH DISABILITIES IN BOSNIA AND HERZEGOVINA AND CROATIA

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**Final report for The Early Childhood Program, Open Society Foundation – London**

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### EXECUTIVE SUMMARY

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This study examines the attitudes and actions of parents of children with disabilities in Bosnia and Herzegovina (BiH)<sup>1</sup> and Croatia. Part of the former Yugoslavia, these two South-eastern European countries have undergone major economic and socio-political changes since the early 90s. Historically disabled children with disabilities suffered high levels of social and educational exclusion in these countries whereas now a public discussion of inclusion and children's rights prevails (Burke, 1994; UNICEF, 2005, 2007; Carter, 2005, Bećirevic and Tsokova, 2009; UNICEF, 2010). To what extent this new rhetoric is reflected in practice and professional discourse varies as shown in this report.

Based on participative qualitative methodology, 89 parents of disabled children in BiH and Croatia shared their views, and discussed their actions in relation to the care and support available for their children. The study has identified promising examples of inclusion, grassroots parents' activism and models of cooperation between parents and practitioners. Parents in both countries were generally dissatisfied with: medical care and disability

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<sup>1</sup> The state of Bosnia and Herzegovina consists of two entities - Federation Bosnia and Herzegovina and Republika Srpska and Brcko District. Federation of Bosnia and Herzegovina is divided into 10 cantons.

assessments; their relationships with professionals and the lack of support at the time of diagnosis and prognosis. Some were more satisfied with their children's inclusion in early education and primary schools and all were very satisfied with the role of parents' organisations in relation to care and advocacy.

Parents' organisations were unanimously viewed as a valuable resource for both parents and children, often serving as a first point of reference for a family as well as helping overcome gaps in state services. This study has identified an important principle - that parents' organisation can serve as a vehicle for inclusion, and more state and international resources need to be invested in supporting advocacy and capacity building of these organisations.

## 1. INTRODUCTION

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The literature pertaining to children with disabilities and their families shows the importance of providing enabling care in advancing inclusion (Clavering, Goodley and McLaughlin, 2007; Clavering, 2007). There is also recognition that policies and practices need to move towards supporting families as a whole in overcoming barriers to inclusion (Dowling and Dolan, 2001; Morris, Barnes and Masson, 2009). Furthermore, it is acknowledged that social inclusion is facilitated by replacing the individual and tragedy based discourses of disability whilst simultaneously breaking down barriers and identifying opportunities for financial independence and empowerment of these families. However this body of knowledge is not sufficiently known or utilised in Eastern Europe and practice has not moved far beyond the official rhetoric.

Recent research in Bosnia and Herzegovina (BiH) and Bulgaria showed that parents of disabled children are establishing parents' organisations and developing practice in parents' activism and advocacy (Becirevic, 2010). Parents in this study stressed the need for improved relationships with practitioners in health, education and social care. Parents' organisations proved to be valuable sources of social capital, support, and information not to mention providers of missing services. However, parents, their organisations and their

advocacy activities are under researched and largely unsupported. Overall, policy makers and professionals have failed to recognise the importance of the parental perspective and their expertise in providing enabling care and improving services and outcomes for children (Goodley and Tregaskis, 2006).

The Open Society Institute Early Childhood Program has shown interest and support for this research due to its long-standing commitment in Eastern Europe to the inclusion and well being of young children through initiatives that emphasize parent and community engagement, professional development, and government accountability. The aim of the current study is to identify how parents can be better supported in providing care, informing policy making and advancing social inclusion at local and national levels. The participatory approach of this research has enabled parents to reflect on their situation and formulate a set of recommendations together with the researchers.

## **Terminology**

*Disabled children or children with disabilities* are expressions that carry different connotations and their use is frequently discussed in the literature. Influenced by the social model of disability, many disabled adults in the UK prefer 'disabled people' denoting the importance of a collective disability identity (Oliver & Barnes, 1998). On an international level 'people first' language is preferred, so 'children with disabilities' is viewed as a more appropriate order of words with the intention of signifying that disabled children are children first (UNICEF, 2005). 'People first' terminology is also used in the UN Convention on the Rights of Persons with Disabilities (UNCRPD), hence this research will adopt this terminology. In addition in some instances, when we talk about educational context or children who do not have physical impairments, we will use the term children with learning difficulties. This is largely informed by the Organisation for Economic Cooperation and Development (OECD, 2007, 2009) studies and efforts to develop an internationally comparable framework in countries of Southeast Europe (SEE) based on the A, B, and C model. This model is an

internationally comparable approach according to which children are registered based on: A) disabilities, B) learning difficulties and C) disadvantage. This new classification will help differentiate between disabled children and children who are still being classified as disabled because of disadvantage, such as Roma children (OECD, 2009).

The term *parents' organisation* is frequently used in this study to encompass a range of grassroots organisations developed by parents of children with disabilities. One non-governmental organisation from Croatia (IDEM), run by professionals and organising a number of activities for parents is also included. The terms *international organisations* are used in this study to encompass diverse supranational and regional aid organisations and agencies, financing institutions and donors (Stubbs, 2007).

## **Methodology**

Ten focus groups were conducted in different towns in Bosnia and Herzegovina (BiH) and Croatia. These towns were: Zagreb, Dugo Selo, and Split (Croatia) and Sarajevo, East Sarajevo, Pale and Mostar (BiH). In total 40 parents from Croatia and 39 parents from BiH took part in this research, 13 parents were fathers and 66 were mothers. The researcher also held informal interviews with another 10 parents who did not take part in the focus groups. The initial plan was to compensate parents for childcare and travel expenses during their participation in the research. It became clear in discussions with parents, that participation did not produce any extra costs as they were held on the premises of the parents' organisations and their children were looked after there. Parents suggested that the money be given as a contribution to their organisations for planned activities.

The focus groups were organised by parents who run the parent organisations and the suggestion was to invite 8 parents, but on two occasions the focus groups had more than 10 parents which was challenging in terms of giving space to everyone to speak. The decision was made not to turn parents away since it was clear that they wanted to take part in the group and hear what other parents and the researcher had to say.

During the research the focus groups proved to be more than a data collection tool. While the researcher went through the planned issues, the focus groups were also a social gathering and a discussion group for parents. There was laughter, sometimes anger about injustices and sometimes tears. On several occasions the researcher was told that the group had been therapeutic for parents:

*'Not only did I feel comfortable but I got filled with some kind of positive energy. I am so glad we got together. I hope we will gather again.'* (Circular email, mother Sarajevo)

*'I really enjoyed it ..., real group therapy. Regards and thanks you.'* (Circular email, mother Sarajevo)

*'I just wanted to thank you for gathering us in one place. I did not have a feeling that I was taking part in some research, it was more like having coffee with friends and talking about everything that's on my soul. Best wishes and good day to all.'* (Circular email, mother Sarajevo)

This research offered participants the opportunity to connect with each other, to exchange opinions, form friendships, and develop relationships. The parents appreciated this participative approach which included being given the time and the opportunity to discuss the research and its methodology and to bring in issues of concern instead of being confined to particular questions

### **Conceptual framework**

This study was based on combining the concepts of inclusion, children rights' and the social model of disability, an approach that is increasingly being adopted by those favouring an empowering approach to the study of children with disabilities and their families (Dowling and Dolan, 2001; Morris, 2001; Campbell 2002; Connors & Stalker, 2003; Bernal, 2006; UNICEF, 2010). These ideas are a strong basis for combating exclusion by directing attention

to the removal of barriers, advocating for increased participation and promoting equality in relation to the role of the family (Becirevic, 2010).

The study reviewed a number of sources that deal with the exclusion and inclusion of disabled children (e.g. Middleton, 1999; Morris, 2001; ECF, 2003; Clarke, 2006; UNICEF, 2007; Morris et al., 2009). It has been suggested that inclusion can be considered to be about *'identifying, understanding and breaking down the barriers to participation and belonging'* (ECF, 2003, p.1). There is agreement that inclusion is a process, not a project or a condition and that societies strive to develop this process through a series of deliberate actions: reducing barriers to participation, reducing discrimination, increasing equality, respecting human rights, learning to value members and improving services.

For disabled children, this means living with their families instead of in segregated special educational and residential institutions. It means being safe, accessing education in their locality, having unrestricted access to transport and community facilities, being able to access leisure facilities, exercising choice, having opportunities, being valued, accepted, and listened to respectfully. Inclusion also enables disabled children to have positive social relationships, be members of the community and have a sense of belonging and achievement, all of which provides a setting where individuals can reach their full potential. This must be the case for all children, not just disabled children; an environment *'where diversity is a norm, rather than the exception'* (UNICEF, 2007, p.1).

Overall, educational and social inclusion discourse is very much about being part of mainstream, non-disabled society. However, this study shows that inclusion is more complex as being with non-disabled children and attending mainstream schools does not necessarily mean that children will participate and be included and happy. There are examples of disabled children developing a sense of belonging and meaningful friendships in special schools or building a positive identity in socializing with other disabled children (French, 2004). So, in efforts towards inclusion, do we consider the diversity of circumstances disabled children live in at a certain point in time, or do we reject outright

arrangements that do not fit with popular inclusion discourse? Reflecting on examples from parents this report tackles this question in the next section through different themes relevant to inclusion.

## 2. KEY THEMES IN BIH AND CROATIA

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This research accessed the views and actions of parents whose children have different impairments or intellectual disabilities, including Down's syndrome, autism, cerebral palsy, ADHD and speech difficulties. Unsurprisingly most parents were focused on the particular condition of their child and how society responds to that particular impairment. Several parents' organisations specialised in addressing particular conditions such as Down's syndrome or ADHD. As one mother said: *'every child is a story for himself/herself'* and this is reflected in the illustrative examples in the research. However there were commonalities in the issues parents presented as summarised under the following themes.

### **Medical care, diagnosis and early intervention**

All parents interviewed pinpointed the time of diagnosis as a stressful and emotional experience. For some parents this happened early on before or soon after birth and for some in later years.

*'I hadn't noticed anything, delivery was normal. During diagnosis they told me that I shouldn't have more children. I went to America with him and did some tests there like magnetic resonance, muscle testing, blood tests to see if something was hereditary. Here in BiH they said one thing, and another thing in the US. The actual moment of finding out is hard, we are normal adults and suddenly they tell you that you have some nasty disease. We try to deal with it, thinking how people will react to us....'* (Mother, Sarajevo)

The relationship with medical practitioners was reported by the majority of parents as problematic. For example insisting on pre-natal screening can be offensive to some parents.



Medical doctors suggesting this procedure need to do so with great sensitivity, and without suggesting termination of pregnancy.

Generally parents felt that practitioners were harsh and pessimistic in communicating the prognosis. Some parents were emotionally scarred by this experience. *'If doctors told me that my child will be the way she is now I would have never cried to start with.'* (Father, Sarajevo)

*'The doctor told me that my child has a plastic brain and he asked me if I have other children. He said luckily there are special schools and when the time comes you can make enquiries about that. He told me so many things my child will not be able to do, but not for a moment that he will be able to do some things...and there was that unfortunate time when one day I came to collect medication for him and the doctor told me –"You know we used to let children like this die before." I cannot talk about that without crying.'* (Mother, Sarajevo)

Doctors appeared to operate within negative, medical centred discourses when explaining a child's disability to parents.

*'What they told me was very, very negative. They said my child will never be able to walk and gave her an autism diagnosis. Now because of the knowledge I generated the child has some traces of it, but with work and persistence my child understands, walks, and participates in this society of ours. She is included in a number of workshops and therapies. Living with her is pleasant, fulfilling and an enriching experience for me and my husband.'* (Mother, Croatia)

Sometimes doctors were constrained by the system they worked in as the number of referrals they could give a day was limited. *'For example a doctor can give five referrals for a specialist today and if you are sixth on that day you cannot get a referral...family medicine complicates things even more'* (Father, Sarajevo). Health care administrators were reported as arranging appointments for children so that families were waiting months and sometimes a year for an appointment at the hospital. While contrary to inclusion policies in both countries, parents testified that some doctors had suggested that they place their child in an institution and remove themselves from their responsibilities as parents.

For parents whose children have speech difficulties it was unclear at what point they needed to seek medical intervention. Some parents received information after a child was five years old, but in some places this was considered late.

*'When my son was three years old I said to the doctor my child is not talking. She examined him and said to me 'shame on you, you have a perfectly healthy child, well developed and intelligent and you are coming up with problems...later when he was five I took him to another country for a medical examination and they said 'where were you until now.'*  
(Mother, East Sarajevo)

When asked about partnerships with medical practitioners most parents laughed and said their opinion was not valued in treatments or diagnosis. When they tried to challenge something that the doctors said, they were considered unreasonable.

*'Whenever I said something they were nodding in a patronising way but my opinions were not considered either in diagnosis or treatment. They did not think that my familiarity with the child or social and family history is important for anything. They would say 'ok mum', and then the established and same medical routes were followed.'* (Mother, Croatia)

*'If you suggest something they argue immediately...but what they write in the history of my child's disease in the long term is important for the future of my child. If there is no diagnosis, there is no rights for social care...therefore that doctor is important to me...'* (Mother, Sarajevo)

To improve the relationship with medical practitioners, parents suggested better communication and information, an emphasis on the positive rather than the negative aspects of the child's prognosis, and sensitivity to the parents' situation and their experiences, *'That moment when you get a child with Down syndrome you need a boost and an understanding what you will be dealing with for years. That is the problem in our system, this lack of communication.'* (Father, Croatia)

*'My daughter was only 14 days old and she had that yellow colour and she was losing weight. We went to a private doctor and she examined her in detail and then said the nicest thing I had heard up until then: 'with her you will enter one world which is different from this one, but not uglier or worse.' (Mother, Sarajevo)*

*'Our paediatrician is a wonderful person. Firstly she brought us literature and I remember the first sentence she wrote in the book: 'Congratulations, you have a baby'- and the book gave information in a nice human way. She also gave us one nice piece of advice- do not deny yourself anything and behave like everything is normal. Go shopping and on outings together and invite as many people as possible in the house and you go to them. When people see your attitude they will behave better too.' (Mother, Sarajevo)*

The majority of parents interviewed said they did not get information from their health care professionals about their child's impairment, what to expect, how the child would develop and his/ her progress. Parents thus were leaving hospitals confused and frightened.

However several parents greatly appreciated and valued a service that included: adequate diagnoses, efficient teamwork in hospitals and receiving timely information about their child's condition. Parents felt that developing adequate hospital policies and guidelines, as well as providing seminars and training for medical doctors was essential in delivering better quality health care in Croatia and BiH.

### **Disability assessments**

Services that strongly influence the lives of disabled children and adults are disability assessments boards, or categorisation commissions, as they are traditionally known in BiH and Croatia. Disability commissions can be defined as official bodies performing disability assessments and are a very important link in a chain of social and medical administration addressing disability in BiH and Croatia. The commission usually consists of a paediatrician, a clinical psychologist or neuro-psychiatrist, a social worker, a defectologist and a medical doctor specialising in a particular impairment (for example an

ophthalmologist or a hearing specialist). In the literature on disability in the region, the categorisation commissions are often described negatively for putting children into specialised institutions (OECD, 2007). The commissions are the only bodies that can legally confirm disability status and the percentage of disability, which is the basis for claiming social benefits, educational support or a disability allowance and pension. Assessing the percentage of disability does not reflect the real needs of a disabled adult or a child. For example, families whose children have intellectual disabilities and no physical impairments are often considered ineligible for financial support.

In both countries all parents interviewed talked negatively about disability assessments because they focused on impairments, affected the rights of a child and exposed themselves and their child to negative questioning.

As mothers in Croatia commented:

*'You have to fight so hard to realise something that belongs to you.'*

*'Why do we have to chase up these papers, perform psychological testing every 3-6 months and plead with psychologist to write you a 'better' test? Because school enrolment depends on it?'*

Disability assessments were needed in order to access financial benefits and school support and in spite of their dislike of the whole process, some parents did not believe they could be discontinued. However there were those who believed that an alternative to categorisation or a modification to the process was required:

*'Let's start with the child and acknowledging and recognising the problem. Let's not think about categorisation straight away, but give support to a child and parents and leave categorisation for later, when a child starts school. Sometimes a child will simply overcome a problem. There should not be a reason why a child should not get a treatment if categorisation is not performed.'* (Mother, East Sarajevo)

It was also suggested that assessments could be performed on the premises of the parents' organisations or community health care facilities. This would reduce waiting time and travel and stress for parents and children. Yearly assessments were not considered necessary when the condition of the child was enduring and permanent.

From 2009 in BiH, financial benefits were only awarded to families whose child was assessed with 90% disability (most severe conditions), a rule which excluded many families from financial assistance. This meant that parents often complained and asked for revisions to the disability assessment in order to achieve a higher percentage of disability. The procedures were anxiety provoking and stressful for parents and children, as well as creating additional costs for the family.

Parents felt that social workers could be the principle coordinators during the times of disability assessment and categorisation and that they could be more involved in supporting parents and children to access their rights. They wanted them to take an active role in making the system more 'user friendly' in terms of accessing financial support and services. They also saw social workers' home visits as particularly important in providing a fair and just service especially with those children who have complex needs and those who live in rural areas

### **Early childhood care and education**

Many parents interviewed had negative experiences with pre-schools and primary schools at the time of enrolment. Rejection by the school was a regular practice, and it was justified simply by *'we do not take on these children'*. Early childhood care was problematic in both countries, but more so in BiH where there were a lack of options for all children. Many parents were refused a place in kindergarten, whilst some came across inclusive kindergartens and were happy for their child to go there. One organisation visited during this research was an inclusive kindergarten which was registered as an NGO but charged as a private kindergarten. Other organizations in Sarajevo were critical of this organisation

because they charged for services. Whilst this could be considered as an example of local inclusion, the service was not accessible to all children with disabilities.

There were occasional good examples of inclusion in early childhood programmes for example in Pale, a small town near Sarajevo. As one of the mothers reported:

*'When the doctor gave us the diagnosis he said the best thing is to enrol him in preschool/nursery. On the third day I went to nursery and explained my problem and the next day brought my child there and it was great. Later lots of kids from there moved on with him to the first grade of primary school and everybody accepted him.'*

Most parents talked of the progress their child had made since starting early childhood education (ECE), *'Luka started ECE when he was 4 years old, and he started to talk syllable by syllable and word by word and now his speech has improved significantly.'* (Mother in East Sarajevo)

A mother in Croatia had had a similar experience:

*'We were lucky because the nursery psychologist was open-minded and said that we could always try ECE for our child and see if this would have a positive effect... Also, we had spent a lot of money on additional therapies and good results are now visible.'*

### **Educational inclusion in primary schools**

Children with disabilities were located in a variety of different educational settings at primary school level in BiH and Croatia. Some were in integrated schools or in special classes of mainstream schools, others in special schools, and there were parents who paid for a private option such as a Montessori school. There were also times when children were out of school permanently or temporarily because of difficulties adjusting or because schools were not adjusted to their needs.

In one focus group in Sarajevo, mothers said that a mother in the group had taken her child out of school. He was a 10 year old boy and had muscular dystrophy. The mother's explanation was that she feared he would fall down and injure himself. He was not in school at all but so far nobody had done anything about it. The mother appeared to have mental health problems.

Parents in BiH were generally more satisfied with educational inclusion and had better relationships with teachers than the parents in Croatia. Overall more attempts towards full educational inclusion were noted in BiH. However, in both countries there were attempts to exclude children with disabilities from mainstream school. Laws on education suggested integration, but left the option of special schools and the formation of special classes if there was a need or if a child had more severe disabilities (Hrvatski Sabor, 2008; Hrvatski Sabor, 2008b).

The Primary and Secondary Education Act in Croatia recognizes three different categories of children with disabilities; children with developmental difficulties, children with educational, behavioural and emotional difficulties and children whose difficulties are caused by social, economic, cultural or language factors (Croatian Parliament, 2008). Dependant on the recommendations provided by experts within the disability assessment bodies, the appropriate form of education is determined. This can either be within mainstream schools where these children are educated according to an individual education programme and can be either fully or partially integrated, the latter meaning that the school has special facilities for children with disabilities.

At the same time, institutionalization is still being practised and children with disabilities are often placed within special schools due to their educational needs although the above law introduces the possibility for inclusion through the introduction of teacher assistants, teachers trained to work with children with disabilities and a mobile team of experts which would assist the process when needed. In 2000/2001, there were around 7800 children with

disabilities within mainstream schools, compared to 3936 that were partly integrated or educated within special schools (OECD, 2007).

The State Framework Law on Primary Education in BiH (Parliamentary Assembly of Bosnia and Herzegovina, 2003) stipulates that children with disabilities are educated in mainstream schools according to individual educational programmes. This law also states that the children with severe disabilities can be educated in special schools when it is impossible to provide adequate education in mainstream school. However parents in the organisation for children with Down's syndrome recently came across a cantonal legislation proposal that contained the option of special schools for children with disabilities. The organisation strongly objected to this proposal fearing that it would be an opportunity for schools to exclude their children. In one canton of BiH, schools are already given the option not to accept children with disabilities if they think that a special school is a better option. A lawsuit has been in progress to challenge this ruling, initiated by the family of a boy who was excluded from mainstream school due to illness and physical disabilities.

The overwhelming majority of parents preferred mainstream schools. There were several positive examples of good inclusive practice from schools in Sarajevo. A parent of the association Radost Zivota commented:

*'My child goes to mainstream school and he is now in the seventh grade and he is doing very well. He does not have mental retardation but is slower than other children. He is the only one with special needs out of 22 children. Cooperation with school is important and at the very beginning you have to make an understanding with the teacher that he will require a different approach and a different programme. At the schools' parents meeting you need to introduce other parents to the issues and ask them to help in teaching their children how to behave towards him. I really do not have any problems, but cooperation was important.'*

Another mother in Sarajevo gave an example where the teacher and other children made exceptional efforts to include her disabled child:



*'That cooperation is very important. I have a girl and she is 12 years old attending 7<sup>th</sup> grade of primary school. Firstly her teacher has played a very important role by developing friendships among the children. Last year the children carried her from one floor to another, but then we got a new school and the lift. I am very happy, Lejla is an excellent student and she has all A's. She did not have any particular problems so we had no need for a special programme. Still because of her physical disability she needed an assistant in her classroom, but we did not have one, the teacher did not have that. Initially when they were outdoors, the teacher had to be with her until other children got used to her.'*

Some parents in this study were sceptical of how their child would fit into a mainstream school and expressed satisfaction with special schools.

*'For now he is happy there; it's a super school. My son is in a great class which includes three girls with Down Syndrome and our son is the fourth pupil with this syndrome. The girls have mild intellectual disability. Today they had school outdoors and my son was delighted. Maybe I would push for a mainstream school but he has serious speech difficulties; he can speak one or two sentences only. In the mainstream school he would be at the bottom of the class with the assistant and would have to fight very hard for this. Hopefully at the special school he will eventually catch up'. (Mother, Croatia)*

Generally, when parents expressed a preference for inclusive options this was not necessarily because of the quality of education, but because of the socialisation it offers to their children. They found that special schools excluded children from the mainstream environment and did not prepare children for the future. In parents' organisations 'SUNCE' and 'Downsy' in BiH, parents were strong advocates of inclusion as the only suitable option for their children and were advocating against accepting any other educational form. According to the parents interviewed, the role of the pedagogue was not always useful in promoting educational inclusion. Pedagogues have been trained to work with 'normal' children, and despite inclusion policies their work did not appear to include working with children with disabilities. All parents' organisations had either a speech therapist or

defectologist who regularly came to the organisation and had one to one sessions with the children. With these professionals, parents had better relationships and partnerships. This research included one observation of the meeting between parents and the speech therapist. The meeting was an update on the children's progress and coordination of the activities of the speech therapist. It was apparent that the parents and the speech therapist communicated positively with respect and mutual understanding, which was in contrast to what the parents had been saying about their relationships with professionals from the state health and social care institutions.

There were numerous examples of problems with educational inclusion, related to the attitudes of teachers and/or a lack of school resources. Some parents gave examples of children being refused enrolment: *'My daughter has a physical disability and they did not accept her in school because of that. Later she had to attend the first grade twice'*.

Parents of children who have ADHD in Croatia reported that teachers did not have an understanding of ADHD and instead punished these children inappropriately by low grades or expulsion from class or school. Some of these parents said that their child had not learned anything in mainstream school:

*'He is hyperactive and has a lack of focus. When they have a test the teacher says "take him away, he is disturbing other kids" and he cannot be in the classroom whenever they have a more difficult module. He hasn't learned anything there. He only learned with the defectologist.'*

In order to support the integration of their child into mainstream school, the majority of parents had to spend some time there. One mother explained: *'until this year I was in the school every second day'*. Some parents attended school because they felt their child would not be safe, or he/she would disadvantage other children. These feelings were sometimes confirmed by the poor environment in the school, and sometimes contradicted. One mother who was against her child going to mainstream school changed her mind: *'The teacher and*

*other children have accepted him, even though I know he does not behave well. They treat him so well, but how much he manages to learn that's another story.'* (Mother, Pale)

Parents often advocated for further development of partial integration (special classes in mainstream schools) as they felt it worked well for their children. As one mother in Croatia commented: *'There should be one school in each area that has special classrooms,'* and another agreed,

*'They are socialising, and they are not isolated. They see each other in corridors; they have lunch together and physical exercise. Those non-disabled children in Kruge<sup>2</sup> do not look at our children strangely at all, and that is the advantage of that school. For them disability is not strange.'*

While children with disabilities did integrate into the daily routines of school, parents said that older children with disabilities were embarrassed to be taken out of lessons for appointments with speech therapists or defectologists. They would have preferred to meet with them out of school time or at least not in lesson times.

Almost all of the 89 parents raised the question of support in mainstream school. The teachers often said they were not equipped to work with children with special needs, as explained by parents with children with ADHD in Croatia:

*'On a few occasions our teacher said, that the work with children with disabilities is not what she has been trained to do, but we have a good relationship with her. Other support staff we have in our school are a psychologist and a defectologist. If I am assessing my relationship with defectologists I would give it 8 and with the psychologist my relationship is very poor. That woman is ok when I am agreeing with everything she says, but when I complained she said how dare you say things like that to people who have been educated for this job...'*

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<sup>2</sup> Kruge is a special school in Zagreb, Croatia

There were different experiences in regards to education assistants as given in these examples: *'We had an assistant, and she was a young defectologist and it worked well until she found another job.'* (Mother, Sarajevo)

*'Our assistant was assigned to Igor and one more child. Igor does not like the assistant and got very angry that he has to have one. He says she is constantly with me and breathes down my neck. Last year he said if she goes on the field trip I am not going.'* (Mother, Dugo Selo)

Some parents said that children did not like the support staff and assistants because they separated them from other children, not because they were not effective in their job.

*'A speech therapist used to come to school, but my daughter does not want to work with him. Sometimes the problem is not in the school, or state or organisation. She wouldn't accept any assistant in the classroom. She does not mind an assistant at home, or after regular school hours, but not in the classroom.'* (Mother, Zagreb)

There were some examples of mothers and fathers having different expectations from the school: *'My wife is more for learning and for pressuring the child and I am more for pressuring the school.'* (Father, Dugo Selo)

There is generally a lack of cooperation between special and mainstream schools and the opportunities for furthering inclusion through collaboration are generally underexplored. However in 2008/2009 the Center for Autism and the mainstream school Mate Lovrak in Croatia implemented a project of developing continuing cooperation. At the individual level, two children with autism were included in a mainstream school with the support of a defectologist, while at the group level collaboration included activities such as school plays, sports events, mutual visits. (Klopotan, et al. 2010).

In both countries, parents feared that their children might be victims of bullying and physical or sexual abuse by other children in schools or neighbourhoods and concerned that there were no established mechanisms to address this. Furthermore the parents did not

know how to address such issues with their children with learning difficulties. One mother was especially concerned, as her daughter of 12 was placed in an all boys' class of a special school. Her anxiety increased when the girl came home with ripped tights and was unable to explain what had happened to her. Other parents were upset by this story and worried how they would address these issues in the future. Children with learning difficulties were sometimes unaware of inappropriate behaviours such as removing their clothes. Parents felt that this was an area where they needed additional support from schools, social workers and parent and community organisations

### **Financial assistance and other benefits**

This study showed that financial assistance was very important for parents of children with severe disabilities and complex needs because these children required a higher level of care and mothers often had to leave their jobs to provide it. In addition these children were more likely to be excluded from educational and community options, which put mothers in the role of constant carers. Financial assistance was also particularly important for single mothers. None of the parents in either country were satisfied with government provisions and gave numerous examples of obstacles in accessing financial support.

Parents were also concerned that they did not have access to appropriate mobility aids. One mother needed 5000 KM (2500 euro) to buy an appropriate motor wheelchair for her daughter, but social services contributed only 800 KM (400 euro).

In the Federation of BiH, financial assistance had been downgraded in the previous two years and only families whose children were categorised with 100% of disability (most severe impairments) were now entitled to assistance. Families received a maximum amount of 360 KM (230 euro) per month classified as personal assistance and home care. The parents needed to justify how they spent this money.

*'You need to show that you withdrew money for personal care every month and how it has been spent. You need to show an itemized (bank) statement where this money went (e.g. for medication, trips to the seaside, etc). To come here to this organisation I need money for*

*petrol, and I always need pyjamas, bedding, sometimes if I am unwell I need to pay a woman to take care of him....'* (Mother, Sarajevo)

If a child was diagnosed with less than 100 % disability parents could only claim child allowance of 42 KM (20 euro) per month. The situation was worse in Republika Srpska as explained by a father in Pale:

*'In the Federation financial support is poor but here it is almost nonexistent. Since 2004 the laws on social care have not been adopted and they say it will not happen this year either. They are avoiding this issue, whilst service users have only 41 K (20 euro) per month.'*

However, employment policies could provide support. According to the Labour Law of Federation of BiH, Article 63, one of the parents with a child with severe disabilities has a right to work half time with full salary compensation. The parent who uses this right cannot be ordered to work overtime or be expected to work night shifts or sent to another position in a company. However this right was only used by parents who worked in state institutions and companies, whilst those working in the private firms were reluctant to claim this right because they feared their employer would not understand their situation.

In 2011 the new Law on Social Care was passed in Croatia (Croatian Parliament, 2011) according to which the disability allowance for children with disabilities amounted to HRK 1250 (170 euros). Parents of children with disabilities were entitled to work part-time and in case of severe disabilities, one parent is defined as the caregiver and is entitled to a monthly financial assistance of HRK 2,169 (300 euros) for staying at home. However, if the child is enrolled in an education institution of any kind even for a couple of hours a day, the disability allowance is cut in half so fostering exclusion.

The financial situation in Croatia for parents depended on who was paying. For example the parent of a child with mild difficulties who attended regular school and therefore their parents were able to work full time received the whole amount of their disability allowance. The parent of a child who was so poorly that he/she could not work or was working part-

time or was on extended maternity leave (which is possible until the child is 8) or who had left their job in order to care for their child had a reduced social welfare payment to compensate for their salary. 'All in all, the poorer your economic status, the lower your financial assistance. This is totally illogical.' (mother in PUZ).

One NGO submitted a complaint to the Croatian Constitutional Court asking for a 50% reduction in disability allowance to be revised. However they had waiting for two years and the complaint had not been resolved.

### **Parents' organisation – care and activism**

#### **Care**

Parents' organisations provided activities for children, speech therapy and defectologist treatments and meetings where parents discussed the progress of their children. The actual support for parents was rather informal and sporadic. Parents were sceptical about counselling, and preferred gatherings and fieldtrips where they could simply chat. When the researcher was conducting the focus groups, parents wanted to carry on and said how much they enjoyed getting together, talking and sharing experiences. Parents were asked whether they could organise support groups and the mother who runs this NGO said: *'Yes, we tried and we contracted a nice psychologist but parents did not want to come to these groups and talk to a psychologist.'* Parents said they preferred an informal environment as a form of support to that of professionally run support groups. According to participants having friends among parents of other children with disabilities was seen as a real resource and the way to find out about benefits, treatments, and exchange information.

There was a lack of respite care. Parents did not have a place they could leave their child for one or two days when a member of their family or their own health was at risk or when they wanted to spend some time with siblings of the child or had a funeral or wedding to attend. Sometimes parents' organisation were able to fill this gap in service, but most of these organisations were not registered to provide all day or overnight stay and could not organize a systematic respite care service:

*'We provide support to mothers as much as we can, she can leave him here if she has to go somewhere, but not for a full day. We work from project to project and have professional support 2-3 hours a day, sometimes even five hours. Some parents abuse this and leave children too long in the organisation. In Slovenia they have day centres, the state built this. Day centres would be a good solution here too.'* (Mother, Sarajevo)

A key issue for good community support would be additional resourcing of parents' organisation, day care centres and respite care. Social work services were not highly rated by parents in one of the focus groups in BiH. One mother, who took part in the focus group in Sarajevo used to work in the Centre for Social Work in Sarajevo, knew a lot about social work practices, but she did not know about the rights of her disabled child. According to the mothers in this focus group in BiH, the social workers were not informed enough about entitlements and rights. For example a mother was advised by a social worker to collect extensive paperwork, including a disability assessment for a benefit she was not entitled to.

According to parents in one municipality in BiH, previously social workers were responsible for one client group – for example adults and children with disabilities. Social workers were now in charge of a particular area and they needed to cover all issues in that area no matter how diverse these issues were. Parents claimed that the social workers had no proper assessments for children with disabilities and discussed whether they could write to the Centre for Social Work and asked if the researcher could help them in creating a data base for disabled children and young people, since the parents had the data.

Because of the lack of support from government organisations, some parents' associations employed speech therapists and defectologists themselves. However some interviewees argued that the role of parents' associations was not to take away responsibility from state health care and rehabilitation, but to strongly advocate for improvements in mainstream services. Furthermore parents' associations can only position themselves as service providers if they have the capacity to do so. For example the organisation for early



childhood education in East Sarajevo experienced numerous problems with local authorities and local schools, and had little assistance.

All parents agreed that siblings needed the support that could be provided in the parents' organisations. Parents felt that they could not give enough attention, affection and time for their other children since the focus is on the child with a disability and siblings without a disability became disadvantaged in the family. One family told a story of their non-disabled child being hurt because she perceived that most of parents' attention was being given to the disabled child. The parents said how painful it was when they realised that their daughter felt this way.

The organisation PUZ in Croatia provided support for siblings which was highly valued by parents. The workshops were a combination of different play that included discussions to inform siblings of the special needs of their brothers and sisters. Support and education was developed in a relaxed atmosphere. Get-togethers, exchange of experiences and fun times such as visits to the cinema, cake shops and field trips were included. Brothers and sisters developed skills of self-advocacy but also gained advocacy skills for their siblings with special needs.

### **Activism**

In some organisations, parents were actively working towards cooperation with schools and they were also advising and supporting other parents in relation to their rights and actions on making inclusion possible. It was mostly parents who ran the organisations that advocated for families on a policy level, commenting on laws and participating in National Action Plans and activities. These parents were also professionals with high levels of education.

There was a need to strengthen the advocacy skills of parents with less education in the parents' organisations. All parents believed that they needed to increase their understanding of policy making processes, so that they could comment on government policies. Currently

these parents advocated for the rights of their own child, but they wanted to learn how to advocate more effectively for the rights of all children with disabilities.

Some organisations had one or two strong advocates who were founders and employed in the organisation. Other parents participated in activities and events and attended meetings but did not see themselves becoming advocates due to their work commitments, care for their child and/or lack of skills. These parents would ask managers (parents themselves) for help in accessing rights or solving particular problems. Training organised by the NGO network 'MOZAIK' aimed to strengthen NGOs internal capacities and involve more parents. As a result of this initiative, one organisation in BiH was involving parents in writing projects, advocacy and raising awareness of disability.

In all organisations visited, there were examples of successful advocacy which changed services or critiqued policies, but especially in; 'Downsy' in Sarajevo, 'Puz' in Zagreb, 'SUNCE' in Pale and 'Angel' in Split. In several organisation parents commented that policies and practises have changed for the better and that older parents have paved the way for younger parents.

*'It all depends on the activities in the association and how much time each parent has. One group of parents was engaged in developing association strategy for the next three years. They were also engaged in writing projects and lobbying donors. Our initial vision was to have our own building, now that we have that we are aiming higher to make this sustainable and to utilise legal frameworks, donor support etc. Currently younger parents and pedagogues are undergoing training for writing project applications and they are applying for one project and if they get it they will manage it from beginning to end. Another venture is Step by Step parenting training when the parents from this organisation will become trainers...'* (Father, Pale)

There were some differences in how parents' organisations promoted inclusion. The organisations that were the most prominent in valuing and insisting on inclusion were - in BiH- 'SUNCE' in Pale, 'Downsy' in Sarajevo and in Croatia 'IDEM' and 'Puz' in Zagreb. The

Croatian organisation 'IDEM', run by academics and experts for inclusion from the Education and Rehabilitation Faculty of Zagreb University put significant efforts into including parents. They built competencies of teachers to work with children with disabilities and published in professional journals on inclusion. Some examples of the work of these parents' organisations include:

- The organisation 'Downsy' in Sarajevo which is active in promoting educational inclusion by: establishing a database of persons with Down's syndrome; supporting marginalised families with financial assistance; organising workshops on inclusive education and increasing the professional competencies of education professionals.
- Parents in 'SUNCE' talked positively about inclusion and were optimistic about inclusion in early childhood as well as primary school years and they were successful in involving the local community in supporting their organisation as well as building the competencies of parents to become trainers for inclusion.
- 'Puz' in Zagreb was active in supporting parents through various workshops, but also in systematic advocacy and lobbying for inclusion in preschool and primary schools.
- Encouraged by parents, the Croatian organisations 'IDEM' and PUZ runs workshops for siblings including playgroups and discussions on building confidence and increasing skills of siblings to advocate for their brothers and sisters with disabilities

The influence of international NGOs that could help and support parents' organisations was stronger in BiH than Croatia. UNICEF, Save the Children, Handicap International and other international organisations, donors and NGOs had an important presence in BiH through financing parents' organisations and conferences, policy making and awareness raising. In Croatia parents said that international organisations were distant and remote from what they did and that they had little direct contact with them. For example UNICEF had a campaign about early childhood, but the parents who took part in this Open Society research only knew about it from television commercials.

### 3. WORKSHOPS IN ZAGREB AND SARAJEVO

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In order to disseminate the results of this study and discuss the implementation of the recommendations, two workshops were held, one in Zagreb, Croatia (11<sup>th</sup> of January 2012) and one in Sarajevo, BiH (12<sup>th</sup> of January 2012). The aim of the workshops was to disseminate the results of the research and bring together parents, donors, government policy makers and professionals in joint discussion on furthering the inclusion of children with disabilities.

In Croatia, academics from the University of Zagreb, Education and Rehabilitation Faculty (ERF) and parents representing large parents groups and UNICEF representatives attended the workshop. The academics and UNICEF representatives gave their comments in relation to the recommendations and took on board parents' views concerns regarding care and support. Representatives from UNICEF expressed their concern that parents were dissatisfied with the system and presented examples concerning positive changes that are happening in Croatia regarding disability testing and support for the education of children with disabilities. They were disappointed that parents were not aware of these new developments and the discussion showed that policy developments do not reach all parents and can lack adequate mechanisms to be efficiently implemented in practice.

In BiH at the workshop in Sarajevo, professional teachers and a member of the government showed an interest in the recommendations and took an active part in the discussions with representatives of parents' groups. Representatives from the Organisation for Security and Cooperation in Europe (OSCE) stated that projects like this can provide information for their activities and strategies. All participants agreed that some laws regarding disability are not well developed and there is a lack of procedures, protocols and definitions when it comes to supporting families with children with disabilities. The workshop discussed how health care professionals came into contact with children with disabilities, that they needed more pre-service and in-service training and that a need for team-work by professionals was an essential recommendation from the research.

The workshop participants suggested that the recommendations need to be sent to the Ministry of Education, Ministry of Health and Ministry of Social Welfare and pedagogical institutes. On behalf of the parents one mother said that this research captured the views of parents very well and accurately conveyed their ideas and suggestions given during focus groups. During both workshops the participants expressed much interest in the presentation delivered by Professor Monica Dowling on services provided to children with disabilities in the United Kingdom.

#### 4. SUMMARY AND RECOMMENDATIONS

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The participatory approach employed in this research has enabled parents not only to reflect on their situation in a number of key areas but also to participate in the development of a set of recommendations in relation to these themes. The parents who commented on these recommendations expressed the view that they accurately and comprehensively captured and addressed their concerns.

The workshop participants who commented on the recommendations also included professionals, donors and policy makers. The workshops were an opportunity to:

- Disseminate the research findings with parents' organisations, NGOs, government representatives and at international conferences
- Increase the profile of the parents' organisations and highlight their involvement in the research
- Stimulate networking between different groups concerned with the education, health and well being of children with disabilities
- Work on developing the impact of the research through government contacts and NGOs responsible for the care of children with disabilities and their families
- Discuss ways forward for the research recommendations' including round table discussions with policy makers, professionals, NGOs and parents in BiH and Croatia

## Recommendations

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### THE HEALTH SECTOR

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- Improved communication and co-operation is required between professionals of different back grounds and parents in order to establish better outcomes for children with disabilities. Practitioners need to acknowledge parents' skills and knowledge in addressing different conditions in relation to their children.
- Medical professionals need to take into consideration the emotional state of parents at the time a child is born or at the time of diagnosis and prognosis. Rather than discussing only what the child cannot do, professionals also need to focus on abilities the child will be able to develop and how parents can aid their child's development.
- Medical professionals need to work sensitively with parents in teaching them how to perform exercises and therapies at home.
- Doctors and other health care professionals need to improve their knowledge concerning parents' organisations and direct new and existing parent to utilise this resource and support.
- Doctors need to be aware that insisting on pre-natal screening can be offensive to some parents. Suggesting this procedure needs to be done with great care and with clear explanations of what the tests and results mean.
- Seminars and training for doctors and health staff in areas of good practice for families of children with disabilities need to be developed.
- Appropriate support for parents in hospitals, including giving parents information about individual disabilities is recommended to avoid situations of confusion and distress documented by parents in this report.
- All hospitals in BiH and Croatia need to improve hospital policies and guidelines concerning the treatment of families with a child with disabilities in order to decrease hospital appointment waiting times and enhance parent satisfactions with the services provided

- The practice of institutionalising children with disabilities is contrary to inclusion policies in both countries and should not be recommended to parents by Doctors or other health professionals

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### SOCIAL SERVICES

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- Policies and practices in Social work centres need to contain information and guidelines for social workers on how to address the needs and rights of families with children with disabilities. This information can make a significant difference to the lives of families with children with disabilities.
- Social workers need to take an active role in making the system more 'user friendly' in terms of accessing financial support and services
- Social workers need to develop evaluative practice and research which assess the impact their work has on service users.
- Home visits with families of children with disabilities, especially those whose children have complex needs and those who live in rural areas is particularly important in providing a fair, just and high quality service.

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### THE EDUCATION SYSTEM

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- Further training and support are needed for the Heads of preschool and primary schools and their education staff on the importance of social inclusion for special needs children
- This research uncovered partial integration in a number of schools. Even though some parents interviewed were satisfied with the effect of partial integration, this is not full inclusion and the effects of partial integration need to be evaluated.
- Children with behavioural problems, such as ADHD are often inappropriately punished at school with expulsion or low grades and there is generally a lack of understanding of these children. This needs to be addressed by policy makers in terms of training, information and support for school staff.

- This research identified issues of poor communication and lack of partnership between parents and schools. More support is needed to develop and evaluate different partnership options between parents and schools.
- The role of the school pedagogue needs to be re-examined in relation to inclusion policies. Further training for pedagogues is necessary especially as these professionals can be the person responsible for supporting parents and teachers in developing partnerships and working together towards the best outcome for a child.
- Education specialists need to make efforts not to take children out of the classroom as older children are embarrassed when they have to visit speech therapists or defectologists in lesson time. At the same time the need for additional therapies needs to be understood by other children as a normal part of their educational experience.

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#### POLICY MAKERS

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- A commitment is needed to implement policies for full integration of special needs children in the education systems in BiH and Croatia with the provision of resources for training in schools and the adaptation of buildings.
- An overall policy of inclusion in both countries is contradicted by policies that leave room for exclusion- such as specific laws on education or poor financial support. Current health, education and welfare policies need to be evaluated in relation to how they support inclusion.
- Policies which simplify disability assessment procedures need to be developed. For example establishing that assessment repetitions are not necessary where the child has a permanent and stable condition.
- The development of 'user friendly' policies such as assessments conducted at the community health premises or the premises of parents' organisations can reduce the waiting, travel time and stress placed on parents and children and provide a better quality of care by professionals.



- The development of policies, and their implementation and enactment need to include the views of parents and children. Education and social policy ministries need to develop 'bottom up' models of service delivery which include the voices and organisations of service users.

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#### PARENTS' ORGANISATIONS

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- Parents' organisations need to develop social activities for families with a child with disabilities so that members of the family are supported to express their views and gain confidence and advocacy skills
- Parent organisations need to be supported in developing communication, business and advocacy plans. This form of capacity building can be achieved through networking with larger organisations working on children's rights or disability.
- In BiH parents' organisations have more contact and collaboration (funding and trainings) with international UN organisations or INGOs. It would be useful to examine to what extent aspects of this practice can be adopted in Croatia.
- Parents' organisations in Croatia are starting to access EU funds and their successful experiences in this area could be transferred to parents' organisations in BiH.

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#### NON GOVERNMENT ORGANISATIONS (NGOS)

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Many recommendations in this report are also relevant for NGOs. Their support, financial resources and initiatives are likely to have a significant effect on the impact of these recommendations. However further recommendations are included here that particularly need NGO support.

- Collaborative efforts by national and international NGOs need to be directed towards including as many children with disabilities as possible in full time mainstream education.
- Initiatives which support early assessment and intervention so that children with disabilities can receive continuous treatment with the specialist and early enrolment

in preschool or preparation for primary school can save additional costs to the health and welfare services later and prevent institutionalisation

## **Conclusion**

The aim of the current study has been to show with best practice examples, how parents could be better supported in: providing care, informing policy making and advancing social inclusion at local and national levels.

These recommendations suggest ways this can be achieved in BiH and Croatia. In essence to better support families with children with disabilities, government organisations do not necessarily need to make major revisions in policies or increase in costing. Efforts need to be directed towards improvements in policy implementation and service delivery. Such efforts would increase communication and cooperation with parents and would help achieve further progress on inclusion for government organisations, professionals and NGOs.

The drive towards EU membership in both BiH and Croatia is a powerful motivating factor for addressing issues of social exclusion and fulfilling the rights of groups such as families with children with disabilities. Parents' organisations need to further build their actions on this positive social momentum. Furthermore the rise of parents' organisations in BiH and Croatia is an indicator of a changing approach in addressing disability. The power of professionals is no longer the only factor influencing the lives of children with disabilities and their families. The parents' organisations included in this research are increasingly participating in policy making and are actively looking for ways that they and their children can be better supported. As this study has shown, participatory research is a good way for parents to identify and document their concerns and put forward suggestions for change.

As one mother in Croatia commented, *'They will better listen to us if we have a scientific approach, if we come out with data and analysis. In that case we can say it is not only the needs of my child, but this is what many of us parents want.'*<sup>3</sup>

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