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## The role of non government organisations (NGOs) in advancing the inclusion of children with disabilities in Bosnia and Herzegovina (BiH) and Bulgaria

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# **The Role Of Non Government Organisations (NGOs) In Advancing The Inclusion Of Children With Disabilities In Bosnia And Herzegovina (BiH) And Bulgaria**

## **Introduction**

Following a long period of socio-political and economic transition, the number of NGOs in Bosnia and Herzegovina and Bulgaria has risen significantly. In the current climate of international pressures and economic changes, NGOs in both countries are seeking to position themselves in what is an unsettled welfare climate. These NGOs have different functions ranging from advocacy, research and policy making to providing various social services. This chapter compares the actions of international and national NGOs, in tandem with parents' and human rights organisations and considers collaborative and conflict approaches from NGOs in working with other organisations. Based on PhD research supported by UNICEF and 15 months of fieldwork conducted in Bosnia and Herzegovina and Bulgaria, this chapter explores the role of NGOs in advancing the inclusion of disabled children (Becirevic 2010).

According to Lendvai (2007, p. 28) South East Europe has a crowded international policy space and for over a decade now it has had a multi-level social policy governance. The aim of this chapter is to map the various influences in disability, inclusion and child care policies currently taking places in BiH and Bulgaria; to identify dilemmas and tensions that come with these influences and to suggest ways forward. The first part of the chapter maps the diverse international influences on the development of social and inclusion policies, whilst the second part presents contradictions and dilemmas that come with this diversity. The final section suggests several ways forward in advancing the inclusion of disabled children and their families through more effective communication with all stakeholders and policies that have a 'bottom up' rather than a 'top down' approach'.

## **Diversity of influence**

Political, economic and social transitions in the early nineties, the (1992-1995) war in BiH and recent drives towards EU integration, introduced strong international influences in both Bulgaria and BiH (Deacon, 2000; UNICEF, 2003; Lendvai, 2004; Deacon & Stubbs, 2007; Saurugger & Radaelli, 2008). Currently the strongest pressure comes from the European Union (EU) and countries aspiring to join have to demonstrate progress in social reforms. The EU in recent years has increased its focus on issues of social exclusion/inclusion, which

affects member, as well as potential member states (Atkinson et al. 2005; UNDP, 2008,2009; European Communities, 2010).

The fieldwork for the research in BiH and Bulgaria was conducted soon after Bulgaria became a full member of the EU. The timing provided an opportunity to discuss with participants the influence of the EU prior to accession and to consider its immediate effects on Bulgarian disability politics. This chapter, overall, is based on views of policy makers, activists and professionals directly involved with policy making or knowledgeable about policies. They were informants from ministries, international organisations (IOs), international NGOs (INGOs) and national and local NGOs. They were asked if they thought that joining/ or aspiring to join the EU impacted on policies in their respective countries. The responses from the two countries varied significantly. Bulgaria experienced very strong pressures, prior to joining the EU, to demonstrate quick progress with social policies.

Before joining the EU Bulgaria was required to reduce the numbers of children and young people in residential institutions and special schools, and to develop policies for education and social inclusion of children and young people from ethnic minorities. One Bulgarian policy maker from an international organisation (IO) commented,

*In the pre-accession period Bulgaria was heavily criticized by the EU monitoring report on the conditions of children and people with disabilities and especially children and people living in institutions. At that time we almost had no community services and family support service and there was quite a pressure on government to start creating different alternatives.*

According to several Bulgarian participants, EU funds were very difficult to administer. The EU style of working was new to government ministry staff and they were often unable to respond to calls for proposals or to access available funds. During the research it was found that even when funds were secured, sometimes due to a lack of personnel and knowledge in a particular government agency, they were not spent. Another concern that was raised by the participants was that the EU requirements on child protection were not a high priority:

*... the whole pre accession was based on making the system aligned with the European Union and since child protection is a domestic issue it's not covered by the key areas and there weren't many specific requirements; it's not like the labour law where you have very specific requirement, or internal affairs that requires very specific legislative changes. Social policy is more open and considered as a domestic issue... (Policy maker, IO, Bulgaria).*

Furthermore, as a majority of the participants discussed, the EU inclusion agenda is frequently misinterpreted by professionals in special schools and residential institutions in Bulgaria. There were occasions when inclusion strategies caused disputes among different policy makers and professionals because of an urgent need to satisfy EU requirements. The participants talked about situations where some residential homes were closed just temporarily to meet the EU demands, whilst children living in those institutions were transported in a rush without notice or explanation to another residential home. This corresponds to concerns raised in the literature by Bulgarian disability activists (Panayotova, 2009). Those policymakers and practitioners interviewed felt that staff in residential homes were threatened by closures and the prospect of losing their jobs. For example one school took the extreme step of frightening the children by telling them stories about how they would lose the only home they had. They also brought distressed children to protest in front of the Ministry of Social Policy to try to stop the closure of this school.

Nevertheless Bulgarian government policy makers confirmed their political commitment to the policies of deinstitutionalisation, a support for family, inclusion and the inclusive education of children with disabilities. Unlike participants from NGOs, INGOs and parents they offered optimistic versions of the current developments. However what happened on the ground in Bulgaria, especially in residential institutions, did not appear to mirror this rhetoric. In addition government policy makers have never challenged or acknowledged the fact that elements of the inclusion agenda are difficult and unreasonably requested by outside organisations, such as the EU.

The participants in BiH had different views and a more relaxed attitude towards EU policies than Bulgarian participants: *'The European Union should be our goal, but within our capacities...we need to be given the opportunity to slowly build society according to the EU standards, instead of just doing it for the sake of gaining membership'* (NGO worker, BiH).

While a major political ambition was EU membership, accession was not certain in the near future and so there was much less pressure to conform to EU directives compared to Bulgaria. Whether BiH will maintain the same approach closer to the actual accession or rush into ad hoc solutions to satisfy the EU requirements remains to be seen.

While the European Union is a major driver of the inclusion agenda in BiH and Bulgaria (Government of Bosnia and Herzegovina, 2009; Republic of Bulgaria, 2010), economic and political pressures also come from other powerful agents. Supranational organisations and financial institutions such as the International Monetary Fund (IMF) and the World Bank (WB) have a powerful role in shaping the future of welfare and social policies in both

countries. In fact, the influence of major stakeholders such as the World Bank, tended to move policy making away from a unified European Union model because of the frequently competing influences of international agents in South East Europe (Deacon, Hulse & Stubbs 1997, Deacon, 2000). Numerous international organisation and international NGOs are involved in social policies and education, for example; the Organisation for Economic Cooperation and Development (OECD), the Organisation for Security and Cooperation in Europe (OSCE), the United Nations Development Programme (UNDP), UNICEF, the Open Society Institute (formerly known as the Soros Foundation), to name but a few. The role of the WB and the IMF Fund is different from other organisations and agencies, since they facilitate reforms by giving large sums in loans and credits which are conditional on specified criteria being met (Stubbs, 2007).

The World Bank declares its aim as fighting poverty and emphasises that disability and poverty go hand in hand (Braithwaite, et al., 2008). They claim to support inclusive development where disabled people and the parents of disabled children are encouraged to contribute economically and to move from benefits to full employment (World Bank, 2008, 2009). It is questionable as to what extent this can be achieved in countries facing high levels of unemployment like BiH and Bulgaria, especially since attitudes and views towards disability, as well as resources, are still at a level that does not permit implementation of these programs. If policies are only focused on labour productivity, excluding other means of support, like cash benefits, disabled children and their families will be pushed deeper into poverty and exclusion. However, a reduction of material support is exactly what the World Bank is arguing for while criticising the BiH government for spending too much money on social protection cash transfers (World Bank, 2009). In Bulgaria the World Bank achieved their goal of reducing cash benefits to a bare minimum (World Bank, 2008) something that the parents of children with disabilities interviewed strongly objected to because they needed financial support to pay high care costs and because there was still a lack of jobs.

In order to save stand-by arrangements with the IMF, BiH, did give in to requests to impose restrictions and savings on pensions, and disability benefits among others. The World Bank requested reductions of 10% in cash benefits before they approved large loans (Dnevni Avaz, 2009). In 2010 the IMF exerted even stronger pressure on BiH to reduce benefits and disability allowances for (1992-1995) war veterans. Even though these allowances were generous compared to allowances for people disabled for other reasons, this measure resulted in demonstrations and fierce political battles by the army veterans (Reuters, 2010).

Apart from supranational agencies, influence also came from various policy 'experts', as discussed by Deacon et al., (2007) who argue that these people have an important place in shaping social policies, but their role is not addressed fully. These policy 'experts' were not interviewed for the research, however their role was also raised by the research participants and it appeared that international workers, consultants, and experts are established as legitimate actors in policy making in the region:

*There were many consultants working here last year in the social area, the World Bank as well; we had a big program on child welfare reform and it was co funded by the EU, but the Japanese government as well and it was meant to bring in good examples... Actually the whole strategy was developed by external experts who worked with the government.... (Policy maker, international organisation, Bulgaria).*

With the promotion of social inclusion, international and national NGOs in both countries developed an influential role in raising awareness about the human rights of persons with disabilities, providing community services, and participated in policy making. There were, however, significant differences in advancing social inclusion between international NGOs, and international organisations such as UNICEF, OSCE, OECD and Handicap International and local NGOs. International organisations had greater power and resources and were more prominent in influencing government policies than local and national NGOs. They participated in popular round table discussions and they commonly led the development of plans and actions.

INGOs were more focused on awareness raising, policy making and research, keeping away from direct service provision unless it was through partnership (funding and monitoring) of local and national NGOs. In addition they involved policy 'experts' who conducted research and published policy reports, which were used by government as needs assessments. National disability NGOs, on the other hand, saw their role as primarily providers of services, with few engaged in disability activism. They often took part in policy making but had much less influence than INGOs and IOs. The tension between international and local agents was influenced by an imbalance in financial and technical resources and in situations where international experts and NGO workers imposed their ideas without regard for, or willingness to support local knowledge. However there were also collaborative occasions when large international organisations provided financing to support national and local NGOs.

## **The Influence of the Disability and children's rights agenda**

The UN Convention on the Rights of Persons with Disabilities (2006) (UNCRPD) has been gaining momentum around the world with many countries signing and ratifying the convention and is seen as a significant instrument in advancing inclusion. However, in 2008 when this research was first conducted, the convention did not have a powerful influence in BiH and Bulgaria and it was hardly mentioned by participants as an instrument that had any relevance to national policies. Still, the disability rights activist in BiH who was present at the UN when the convention was discussed said:

*I had an opportunity to see how much the BiH delegation advocated for acceptance of the convention, especially the act concerning disabled children...however our country still has not signed let alone ratified the convention. ..and that is maybe the biggest problem. To be honest I do not know to what extent the country is ready for it. The standards rules have been adopted in 2003, but they are not obligatory. The convention is indeed obligatory and that is probably the reason why is still has not been signed (Disability activist, NGO, BiH).*

By 2010 the UN Convention on the Rights of Persons with Disabilities (2006) had been signed by both BiH and Bulgaria. However it had been only ratified by BiH and this came after strong pressure from disabled peoples' organisations.

The United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (1993) were highlighted as the instrument that has contributed the most towards advancing the position of disabled people in BiH. Organisations of people with disabilities in BiH actively promoted these rules, so that in September 2003 they were adopted by the Council of Ministers of BiH as a document that needed to be used as a basis in policy making (Cehovic & Zahirovic, 2006). The UN Convention on the Rights of the Child (1989) was also mentioned, especially by IOs and INGOs, as a good basis for advancing inclusion. Both BiH and Bulgaria signed and ratified the UN Convention on the Rights of the Child (1989) but the rights of children, especially disabled children are too frequently violated especially in the case of article 12 on child participation. This can have grave consequences, especially if the state is considering placing a child in an institution:

*The Commission in Centres for Social Work decides whether a child will attend mainstream school or go to residential special school or an institution. In this situation a child is not really asked. The UN disability convention states that the opinion of the child will be considered in decisions regarding that child. I think it was in fact the*

*suggestion of BiH to incorporate that article, but this is surely about children who have mental abilities preserved. We cannot expect from a child with mental retardation to decide where and how he/she will live and go to school... (Disability activist, NGO, BiH).*

When it comes to disabled children, especially children with intellectual disabilities, a main postulate that 'rights apply to all children' seems to be forgotten. Furthermore there are misconceptions in applications of these rights. Professionals, even disability activists expressed opinions which could be interpreted as a social acceptance that human rights fulfilment depends on social conditions, good will and the nature of the impairment. Since rights are unconditional one would think that these violations would be recognised by the UN committee, monitoring rights implementation, which would then instigate remedial actions. However, one Bulgarian activist talked about how this was not the case in practice and how organisations competed and misinformed one another when it came to UN committee hearings. According to this informant there were lobbies within the country, which wanted to present a particular picture and they tried to exclude those who had different findings, especially those who were very critical of the situation in relation to children's rights.

The usual procedure is that at the UN committee hearings the countries present a state report and an alternative report. The alternative report is usually compiled and finalised by an INGO that often takes the lead in doing so of its own accord. Information can be rather selective or they might not have a sufficiently nuanced picture of what is happening in a particular areas, such as disability. The work of NGOs, INGOs and IOs, do bring in new ideas and opportunities for inclusion, however throughout the study it emerged that the social inclusion field is also loaded with tensions, dilemmas and contradictions.

### **The search for a welfare model**

Even though the EU and international agencies have the same broad inclusion agenda for the Region (UNICEF 2007; European Commission, 2009; OECD, 2009), implementation strategies vary significantly. For example parents of children with disabilities expressed the need for financial support in overcoming exclusion. However policy makers in BiH and Bulgaria expressed different views. In the Federation for BiH, there was agreement on increasing financial assistance to families as specified in the Amendment of the Law on Social Care (Government of BiH, 2006). Bulgarian policy makers however, argued against this approach, claiming that increasing financial assistance would create dependency and foster poor productivity. Their policy approach was to provide community services for children and employment for the parents. This policy approach appeared to develop from the



pressing need to overcome institutionalisation but also because they had been exposed to closer scrutiny by the EU, IMF and the World Bank (Panayotova 2009).

There are also unresolved issues in how changing welfare models reflect an inclusion agenda. Wagener (2002) argues that the communist welfare state was very different from the European (EU) model and that the countries of Central and Eastern Europe need to achieve the transformation of their political and economic system, including catching up with productivity levels. In communism, welfare was a worker's privilege rather than a citizen's right. In daily life, of course, the difference was minimal, since almost everybody was a worker. Wagener argues that the convergence of social conditions will be the outcome of economic convergence; it cannot be its precondition. Hence, candidate countries need to be free to choose welfare regimes which they think are appropriate for their stage of development and their social culture. However due to international pressures and loan conditionality, achieving this goal might prove challenging.

In relation to disability, the Bulgarian system is now more oriented towards labour productivity and community services, avoiding cash benefits. The BiH social policy system was for many years exposed to a complex mix of humanitarian and security interventions which directly affected the processes of social and political change (Deacon & Stubbs, 2007). The transition from communism and socialism in BiH was different from the transition in other countries, since BiH was not exposed to what Stubbs (2008, p. 4) calls a 'shock therapy of neo-liberal adjustments'. Instead a humanitarian approach for a long time dominated international influence. The effects of this influence are still felt and the needs of disabled people and children are often met through the works of humanitarian organisations. The image of humanitarian actions is not easy to shake off and there are those who still see NGOs and international organisations as organisations delivering humanitarian aid instead of being agents of political action and change. This is a difficult tension to resolve as humanitarian aid provides the cash and assistance to vulnerable families, but relieves the state from responsibility and undermines a rights based approach.

However, the humanitarian approach in BiH is possibly acting as a buffer to the neo liberal agenda promoted by the World Bank in the Region. The World Bank advocates privatization of health insurance and the promotion of productivity above social safety, which impacts unfavourably on disabled children and their families. With their neoliberal agenda, the World Bank contradicts the EU social solidarity model (Deacon et al., 2007), which has a direct implication for the inclusion agenda. One of the participants in Bulgaria highlighted the contradiction between the inclusion rhetoric and the reduction in financial and human

resources in social work centres. Institutions like social work centres, schools and community centres need to be strengthened to cater for the diversity of the population and this will require resources. Naomi Klein in *Shock Doctrine: The Rise of Disaster Capitalism* (2007) strongly criticizes the World Bank's neo-liberal ideology arguing that it destroys indigenous capacities and exacerbates poverty. Klein (2007) argues for a mixed economy where developing nations are not coerced by the developed Western nations who run the IMF and World Bank, but are allowed to choose their economic destiny. However developing nations because of pressing needs for funding are tied in to Western economic plans.

Both Bulgaria and BiH are adjusting to a mixed economy of welfare, from the bureaucratic state collectivist system of welfare and state paternalism that dominated Eastern Europe (Deacon, 1992). In addition there is a popular political rhetoric among policy makers in both countries that policies need to be adjusted to a 'Social European Model'. However they fail to acknowledge that there is no clear European Model, nor a common understanding of what the characteristics of EU welfare in current member states are (Deacon & Stubbs, 2007). In addition it must not be forgotten that economic indicators in BiH and Bulgaria are much poorer than those of Germany, the UK, Italy or France and this inevitably reflects on welfare development indicating that the social model cannot be the same across Europe.

### **Policies, transfer, translation or a project?**

The tensions and dilemmas around the social inclusion agenda arose because of numerous examples of unsustainable, as well as unhelpful and contradictory strategies among different stakeholders. Policy making in both countries was influenced by the actions of foreign NGOs, which often looked for quick solutions from developed countries of the EU. It appeared that in Bulgaria, the UK was very influential in bringing in new policies as commented on by a policy maker from an international organisation:

*.... in the UK you can do it as a pilot model and if it proves successful it will continue; in Bulgaria it doesn't matter if it is successful or not you have to change it in legislation. The model can be very good, but legislation takes time and then you've lost it.*

The presence of international agencies and foreign consultants in South East Europe (SEE) could be seen as encouraging policy transfer (Deacon et al., 2007). However Lendvai and Stubbs (2007) put forward the idea that the process of policy translation rather than policy transfer is more appropriate to describe policy processes in SEE. Policy translation is a more fluid and dynamic process where policies are not copied in their original form but are

constituted by multiple actors, networks and policy brokers. Whether policy transition takes into consideration the fit with local conditions and sustainability, is not always clear. The policy makers were asked how they constructed policies and whilst there were strong indications that they looked for examples from abroad, the straightforward transfer does not happen:

*In policy making we usually look for examples from abroad. However, this usually shows that they cannot be applied directly here. I don't like the fact that we always try to translate policy making initiatives either from the region or from the West. We need to recognise that Sweden, Norway and the UK have much better standards when it comes to policy and practice so we cannot really copy them exactly (NGO worker and policy maker, BIH).*

It has been reported that the development of policies in the field of disability is increasingly conducted with the participation of disability activists, who are sometimes disabled people themselves or parents of disabled children. However their opinions are not always respected as the mothers from parents' organisations reported. This was confirmed by a Bulgarian policy maker from INGO when asked if parents participate in policy making: '*... it's supposed to be. In practice it isn't really the case*'. In commenting on the currently popular model of strategies and plans of actions, a government policy maker in BIH said: '*Those strategies are often the outcome of individual projects and are not based on assessment of the actual situation*'. This was also the case in Bulgaria, where parents and informants from INGOs and NGOs stressed that the needs of communities were not assessed and researched. This approach resulted in a situation where services in some towns have no users, whilst in Sofia for example there is a great demand but not enough day centres. Furthermore, Bulgarian parents and NGO workers claimed that research could establish what clients need and help in creating diverse services, instead of offering the same to everybody.

Domestic policy makers are unsure how to carry out the process of harmonising national legislation with the EU legislation (Young & Quinn, 2002). One policy maker said that these processes are very unclear to domestic stakeholders, who look for similar laws and regulations in other countries, but these are not readily available. What usually happens is that international agencies put on strong pressure on government ministries, bring in their experts, engage NGOs and provide an injection of funds for solutions to be accepted. This results in a situation where policies or strategies are not embraced by all stakeholders, with some refusing to take these new developments on board. In addition participants in both countries argued that these policy documents are loaded with messages about children's

rights, equality and non discrimination, but lacked implementation and enforcement mechanisms, as illustrated by the following comment from a Bulgarian policy maker from an international organisation:

*In Bulgaria, in order to be implemented, a policy or strategy has to be transformed in legislation. I did an assessment of all policies concerning children and their rights and there were 22 of them; there was strategy for children with disability, for street children, for children in institutions, I mean everything that you can think of. None of them was budgeted for and frankly, very few of the measures were really implemented.*

Several practitioners claimed that the parents of disabled children advocated for the individual needs of their child, instead of using their experience to advocate for all disabled children. These claims are however contradicted by examples of parents' activism in both countries. Parent organisations were highly praised by parents and it is sometimes the only place where parents and children get much needed support. In fact parent organisations are becoming increasingly recognized by professionals themselves, as noted by this defectologist in BIH:

*You need to visit parent associations here; they are very transparent, they are doing a great job, I can only congratulate them...After all they are parents of those children. Imagine what a defeat that is for our profession, when a parent association shows better quality in certain jobs than defectologists do. That is like some kind of deterioration of defectology... (Defectologist from special school, BIH).*

Overall this research indicated that policy making did not reflect an inclusive approach and that children were not asked what they thought about policies and projects that are developed for their 'benefit'. An important contradiction within social exclusion policy is that it excludes the people and groups who are socially excluded from the debates. ( Warren & Boxall, 2009). The situation may be slightly better for some groups such as Roma, and disabled adults, but disabled children are completely excluded from the discussion. This is especially the case for children who have intellectual impairments and/or those who do not use speech to communicate.

## NGOs and Inclusion

While in the UK, disabled peoples' organisations have made a major impact on disability politics and policies (Barnes & Mercer, 2001; Oliver, 2004), this research demonstrated numerous complex issues around the work of NGOs in BiH and Bulgaria.

Even though NGOs occupied an important place in advancing inclusion, bringing in new practices and generating social change, the position NGOs occupied was not clear. They frequently had to compromise between struggling to keep their organisation going, increasing their profiles and providing services. Several participants in this study expressed doubt that NGOs were able to bring about social change and advance inclusion. In Bulgaria, this was because most of the national and local NGOs were established with people who used to work in the old system and were responsible for the exclusion of disabled children. They did understand why the system needed to be changed but their lack of professional capability and knowledge was evident and has been also mentioned in the literature (see Maglajlic-Holicek & Residagic, 2007). There have also been concerns over financial transparency (DFID, 2005). These issues were reflected in fieldwork interviews. For example a government policy maker remarked:

*In BiH we have an 'aristocracy' of NGOs where around ten of them have a monopoly and they do not share information. When we cooperate the partners are individuals and not organisations...most of the resources are used on their expenses and travel. There are no mechanisms through which government can give support to disabled individuals through NGOs.*

These problems are more acute in cultures burdened by poverty and inexperienced in civil society actions. Key issues that were evidenced in the research included: following donors' agendas rather than the expressed needs of communities; the development of short term 'project cultures'; an emphasis on building organisations instead of addressing social goals, and distancing NGOs from grassroots activism (Stubbs, 2006).

The major growth in the number of NGOs in the past 10 years has been related to the actions of international donors and according to Maglajlic-Holicek and Residagic (2007), instead of being truly civil organisations, they now resemble a private business sector focused on absorbing donors' funds. Experienced professionals from the social sector are excluded from working with the international NGOs if they do not speak English. Furthermore evaluations of the projects are frequently conducted without users' participation (Maglajlic & Hodzic, 2005). Problems with monitoring the work of NGOs was mentioned in

both countries, as one Bosnian participant commented: *'no-one is able now to monitor them to see what kind of quality they provide, what kind of capacities their services have'*.

With national and international NGOs becoming official and unofficial providers of services, tensions about the quality of services provided have been highlighted. In BiH professionals from government institutions expressed suspicions about the way some NGOs work and the services they provide, especially around independent living for disabled young people. In Bulgaria however NGOs were critical of the quality provided by government agencies:

*The quality of the services goes down after the municipality takes over.*

*Unfortunately, the situation is that when the municipality starts to govern these NGO activities, they put in staff that are not so well qualified, but they put these people in because of their private relationships (NGO, Bulgaria).*

INGOs sometimes provide desired community services such as play groups, toy libraries, preschool services and mobility aids temporarily which created a false impression of true improvement and change. Furthermore different NGOs and donors worked to different agendas, sometimes not clearly thought through. The following quote illustrates this point:

*...British, French and German NGOs donated really enormous amounts of money to residential institutions ... and now after several years they see that everything is stolen or hidden and none of the toys or equipment they provided is used....because there are no professionals, but they never, never think about the people...I say to them NO you should pay salaries, you should train people and never buy clothes, shoes, but that is the donor mentality, they continue to do that... (INGO worker, Bulgaria).*

The problem of corruption and nepotism was raised by several participants in Bulgaria. They gave examples of the misuse of donations by people who run homes for children and amongst officials and people in power who employ staff in child care centres and services. not according to the knowledge of the staff but because of personal connections. Allocation of government's funds to national and local NGOs, as expressed by both BiH and Bulgarian participants was not always done on the basis of the NGOs capacities, but on their good or bad relationship with particular ministers and personal lobbying. In 2008 Bulgaria, was excluded from receiving 500 million euro in financing from the EU European funds due to corruption (Castle, 2008).

This study has identified a patchwork of frequently contradictory government, IOs, INGOs, and national and local NGO initiatives in disability policies and practices. These contradictions sabotage clear social inclusion plans so that some stakeholders invested in the improvement of residential care whilst others were closing down as many residential care facilities as possible. Some policy makers advocated for the reduction of financial assistance to parents, some advocated for an increase, in order to advance inclusion.

### **Ways forward**

Considering the evidence it appears that resources as well as the global inclusion and human rights agenda that come with international agents, are not sufficiently utilised in BiH and Bulgaria. Foreign players exert power over domestic policymakers, a power which is not always productive, but domestic stakeholders are apprehensive about criticising their actions. Therefore some of the actions are officially endorsed, but simply passively resisted (Deacon et al., 2007). These issues need to be addressed by all national stakeholders, who need to be more proactive in cooperating with foreign stakeholders, from international NGOs to big donors, creating a window for debate. In addition, government and non government organisations need to coordinate their efforts towards inclusion; so that they can influence donor agendas and avoid programmes and projects that are not fulfilling inclusion principles. Coordination could be improved if policies were developed systematically and evaluated regularly, with users' participation, something that is not currently occurring (Maglajlic & Hodzic, 2005). Competing and sometimes contradictory inclusion strategies can be overcome if inclusion is debated as a national policy agenda, addressing all opportunities and constraints in the current context.

Furthermore public stereotypes and the way disabled people are portrayed in the media and discriminated against in public needs to be exposed and challenged. The language around disability and inclusion is very much scrutinised in disability literature in the UK (Barnes, 1992; Oliver & Barnes, 1998) but the same scrutiny was not encountered in BiH and Bulgaria. Moreover language needs to be given additional attention because of policy transfers and translations that are currently taking place, which are tied to particular language and discourses. This chapter showed how concepts such as inclusion can be misunderstood and lost in translation, reinforcing the idea that culturally appropriate terminology and understandings of concepts need to be developed. In addition the presence of children's rights organisations and their involvement in policy making is an opportunity for strengthening a children's rights approach to inclusion. This is an opportunity

to move the policy agenda and the way policies are developed from a 'protective' understanding of childhood to one in which children are given participatory rights.

When a project fails to achieve sustainability or when initiatives do not take off in a non-western country, international NGOs tend to blame cultural influences for this (Burr, 2004), a problem recognised in this study too. International organisations need to change their approach in BiH and Bulgaria and start taking existing practice more seriously, instead of what Burr (2004, p. 156) describes as '*presenting themselves as rescuers and sole defenders of children's rights*'. According to Deacon et al. (2007, p. 238) '*the specific ways in which IOs relate to local players matter. They mould local knowledge and expertise, strengthening some think tanks and scholars and not others. They co-opt scholars into IOs, dissolving potential criticisms...*'. An example from the fieldwork included: excluding national professionals, if they did not speak English and did not conform to a particular agenda.

Working in IOs and INGOs can be a negative practice if it deepens the gap between international and national agendas and creates the existence of two opposing groups. It can also lessen the opportunity for appropriate cultural translation. It would be beneficial to overcome this practice and combine the first hand experience of BiH and Bulgarian social workers, teachers, medical doctors with new developments and international best practices available through international organisations.

This chapter has considered a number of factors and players that contribute in creating changes in policies, practices and the overall situation with the disability agenda in BiH and Bulgaria. Undoubtedly there is no lack of agencies, organisations and diverse influences that work on promoting inclusion. The international human rights agenda is slowly creating a better atmosphere, as is EU accession and the actions of international agencies and national NGOs. However, the strong presence of diverse actors in disability policy making has both positive and negative effects, which are hardly debated. This period of change and diverse influences could be an opportunity for debate, but also an opportunity to avoid the slowness of developments in the West and to use experiences from the West to advance inclusion.



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