

# **Bolton Data for Inclusion**

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## **Title :**

*Worlds Apart: The Struggle for Inclusion in Bosnia and the UK*

## **Abstract :**

*This data describes a visit to Bosnia to meet families involved with the struggle to include their disabled children in local mainstream school, despite the ravages of a recent war. Important lessons have to be understood if we are to rid our society of an institutionalised rejection of diversity; where individuals are labelled, segregated and isolated for being seen as different.*

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**“Dear Teacher,**

**I am a survivor of a concentration camp. My eyes saw what no man should see. Gas Chambers built by learned engineers. Children poisoned by educated physicians. Infants killed by trained nurses. Women and babies shot and burned by high school and college graduates.**

**So I am suspicious of education. My request is that teachers help students become human. Your efforts must never produce learned monsters, skilled psychopaths, educated Eichmanns. Reading, writing, arithmetic are important only if they serve to make our children more human.”**

*Haim Ginott (1972) Teacher and Child*

Remember “Yugoslavia” as a holiday post-card? Remember the six o’clock images of frightened faces behind razor wire fences, the agony of separated families, the roads choked with refugees, the sites of mass executions? Now the “former” Yugoslavia is recovering from a war in which “former” friends, neighbours, workmates, students and families ripped out the very heart of community, segregated, divided and “cleansed” it whilst the rest of the world stood by and watched. What, if anything, can be understood about these events and our own complacency in the face of such appalling suffering? What does all our fine talk about “inclusion” amount to when confronted with this awful reality? When and where do we begin to learn?

In Bosnia, four years of war has not in any way diminished people’s capacity for passion, life and warm hospitality. Yet the reminders of conflict are everywhere; postcard villages disfigured by the shells of burned out homes; the peace of the countryside disturbed by the rhythmic thudding of military helicopters; a busy market place and town square “policed” from a distance by a group of heavily armoured United Nations (UN) troops; an illegal shanty town market in a featureless area known as the “Arizona Corridor” where Serbians, Croatians and Muslims trade freely in cigarettes, alcohol, clothes and food, much to the frustration of their respective governments. Given the bitter ethnic tension, heightened by the possible withdrawal of the UN protection forces, it was startling to learn of the emerging struggle of many parents to have their disabled children included in the reforming communities; a struggle for inclusion and the right to an ordinary mainstream education.

Evidence of this “inclusion movement” first appeared in accounts by a relief organisation, notably Oxfam, who had been working with young disabled people and their families throughout the war.

Curious to know more about this work and the reconstructing attitudes to disability and inclusion, we made two trips to Croatia and Bosnia in the Autumn of 1997.

In Zagreb, a principal city in Croatia, we were met by two friends and colleagues, Borka and Yasmina, both Professors in Education from the University of Zagreb and both closely allied to the struggle for Inclusive Education.

We had briefly met Borka several years previously at a conference in America where 5000 people from all walks of life and all parts of the world had gathered to debate the issues of Inclusion, Community, Disability and Education. However, with that short space of time we had shared our experiences of people’s struggles for recognition and basic human rights. There was a resonance between us, reinforcing convictions about the common cause of dispossessed and disenfranchised people, the “refugees” of all societies. After a number of telephone conversations and letters over two years, whilst the war in Bosnia escalated to real but unimaginable horror, a strengthening of those convictions evolved along with a greater personal immersion in the struggle for inclusion in our own limited and often frustrating areas of work.

In 1995, Borka had been invited to lead a project at the University of Tuzla in Bosnia. She had taken with her the underpinning philosophy of inclusive education to a setting where such a model might appear to have little chance of success. However, after several visits to the University she met with many families who were engaged in this struggle to have their children included into their local ordinary schools. They were not looking for or expecting an educational technique, they were not looking for something “special” they were wanting their children to be accepted, to belong, to contribute, and to be loved. Her wisdom and far-sightedness brought together education professionals and parents in a common enterprise. The relationships and joint energies resulted in powerful partnerships within an apparently hostile environment.

We were invited to share and contribute to this partnership in a way that initially made us question our possible input. However, the strength of our common convictions helped us to

identify the barriers which had to be challenged; the recognition of unjust “man-made” barriers and labels which prevent children playing and learning together; the recognition that the barriers which prevented such reasonable expectations were commonly maintained by faceless government departments and bureaucracies; the recognition that such bureaucracies were strengthened by their isolation from individual stories and the lives of ordinary people; the recognition that the futures of these individual children and their families were being limited by traditional medical thinking and by a lack of concern and vision for a better future.

After discussing these issues for a day or two in Zagreb and preparing for the visit to Bosnia, we travelled by bus for five hours to a forced border stop in total darkness at the edge of a broad, swift flowing river. Across the water, lights glided slowly towards us. This river, the natural boundary between Croatia and Bosnia, had been passable in seconds on a modern flyover before the war. Now, the bridge gone, the only way to cross was by a small pontoon which was pushed back and forth across the river by an ageing tug-boat.

The approach road was cratered, making the movement of the bus unpredictable as it grumbled slowly down towards the river in the darkness. We finally edged onto the pontoon which then took us silently and nervously to the other side.

At this point the tension and excitement of entering a foreign country was vivid in a way too rarely experienced in this modern era of fast, cheap air-travel, between airport capsules. This was unmistakably an unknown territory and there were many assumptions about ourselves and Bosnia which we were about to unlearn in a short space of time.

It was miserable, very wet and very late night when we arrived at the bus station in Tuzla. We were greeted by a student from the University who insisted on taking us for a meal and drinks. Our Serbo-Croat wasn't as sharp as it might have been and, as the preferred second language of local people appeared to be German rather than English, we were dependent on Borka and Yasmina for translation throughout the visit.

Our first port of call the following morning was to meet students from the University who were a new group looking at the significance of Inclusive Education. They were working from a set of profound personal experiences learned during the years of conflict:

**“We did not have inclusion for disabled children before the war. They would be sent away from their homes to special schools. I know now that we have to do it.”**

**“We are not only against the segregation of disabled children, but the segregation of older men and women. Differences are natural and good. It is not our right to disturb such differences by separating them.”**

**“Including children in the regular schools in kindergarten is very important. It is essential to start at the beginning of the child’s education.”**

Later we arrived at the Koraci Nade (Steps of Hope) Centre to a warm reception from children, parents and staff. The Centre is based in sparsely furnished rooms rented from the University. It has been funded and supported for five years by Oxfam as part of their international relief work in Bosnia. We had first read about the work of the centre in Rachel Hastie’s book *“Disabled Children in a Society at War”* (1997 Oxfam). It was surprising to learn that Oxfam was attempting to operate within the “social model” of disability. Unlike the “medical model”, which has shaped much of traditional service design and focuses on a person’s impairment and the pursuit of “cures”, the social model points to an achievable goal which lies in the restructuring of attitudes.

**The social model suggests that:**

**“disabled people’s individual and collective disadvantage is due to a complex form of institutional discrimination as fundamental to society as sexism, racism or heterosexism.”**  
*(Mason and Reiser, 1994)*

This also means that the philosophy of inclusion and the human rights of disabled children and their families were the guiding principles in Oxfam’s work in Tuzla. Prior to the war disabled children had been sent to large institutions around Yugoslavia, this resulted in fractured family lives and the loss of children to places where families could have little contact or access. As a result of the war they were returned home to their families without any provision for support, education or day-care. It now appears ironic that the ravages of war brought the children home to their local communities.

This, for many, continued to be a life of uncertainty and much deprivation. However, it did highlight for the parents the importance of being together and the potential for meaningful relationships to enhance their lives in sometimes desperate situations. Projects like the Koraci

Nade were therefore an attempt, in a small way, to meet some of these urgent needs. Perhaps unexpectedly they also provided a springboard towards the recognition of the significant contributions that disabled children could make to their families and communities.

People involved with the Oxfam project were themselves prepared to be guided by new ways of thinking which had actually evolved in, supposedly, more innovative practice in other western countries with better resourced education systems. The opportunity provided by the project also highlighted the importance of the acceptance of diversity and different abilities in enhancing the quality of community life. Such a lesson is much needed if we are to rid ourselves of the destructive practices of segregation, devaluation, fear, ignorance and intolerance which, unchallenged, have resulted ultimately in the horror of ethnic cleansing and the gas-chambers.

The Centre supported children and their families by providing:-

- A place where children could learn to be with each other through play.
- A place where parents could get information about the availability of support.
- A meeting place for parents to share their experiences.
- A place where staff and parents could explore new possibilities of integration.

The concept of inclusion was initially regarded with scepticism by many of the staff at the new centre but gradually it came to be accepted as the only way forward.

**Fata Ibralic, one of the project workers explained:-**

**“In the beginning it was difficult to understand Oxfam’s approach, but after thirteen months of working in the Centre, I began to see that children learn much better from each other. There were some problems with the non-disabled children at the start with prejudice and fear, but after they had been together a while they just naturally started to play together. This Centre is very important to us and we are trying to achieve something not tried before. It is the first step towards an integrated approach to disability in Bosnia.”**

**Azra Begtasagovic, a disabled person herself, was trained and employed as a physiotherapist at the Centre. Recalling the experience of one of the children coming into the Centre in the early days of 1994, she said that:**

**“Once she had started coming to the Centre and mixing with other children she started to progress almost immediately. Children need to be with other children. In the institution the doctors with white coats in cold rooms can frighten them. Here they are surrounded by toys, laughter and their friends. When we play some games, all**

**the staff, the children and their mothers play together. It's fun and relaxing. Before the war there were only institutions. Now children can get some help near their homes and parents can be involved too."**

During our visit it was made clear that the project was in danger of coming to an end due to a lack of funding. The question of the continued funding had been a concern for some time and there had been discussions between Oxfam, Local Government and other relief agencies. It had been decided that one way forward was to incorporate the project with a local school; 'The Kosta Popov Special School'. Our understanding was that this had not been Oxfam's first choice but it was seen as the only way of safeguarding the project's long term future with the co-operation of the Local Authorities.

We were to visit the school and witness at first hand the potential for the project's development within the new setting. We were totally unprepared for the experience awaiting us. On arrival it was clear that we were not going to meet any of the children. We were immediately ushered into the "Director's" office, and were struck by the clear lack of hospitality of the sort we had come to accept as the norm in this part of the world. The Director responded to us coolly, in a way that he had obviously rehearsed with many previous visitors, itemising the wonders of the new extension to the school. The rhetoric was a reminder of many previous encounters with people in positions of assumed authority that control the built environment of the special school. Extolling the virtues of spacious classrooms, the dining areas and communal toilets, he made no reference to the purpose of education within this building or the needs or lives of the children it was designed to serve.

After a fifteen minute monologue we were taken around the new building by the proud Director, room by room and key by key. As each door was unlocked we stared at yet another empty space without staff or children, memories of polite visits to similar "state of the art" segregated buildings in the UK came depressingly to mind. This, again, represented institutional provision, newly packaged, sanitised and emotionally sterile, without reference to the needs of the children or families it was to serve. The extension to the special school had been funded by an international relief organisation to the tune of several million dollars.

This was, yet again, an indication of the potential damage in providing material relief without belief in any underpinning set of values. This "relief without belief" philosophy allows local

authorities and other agencies to provide considerable financial resources and buildings with little, if any, reference to the views of those served or the advocates. Expedience without understanding dictates that it is the views of the people running the service, who clearly have an interest in maintaining the status quo, which acquire a disproportional importance. Fundamental to any effective service has to be the practical engagement of the individual whom the service is being provided for. For instance, disabled people have to be at the forefront of any decision making or service design, when providing services or devising policies for disabled people. Equally, non-disabled professionals have to recognise that their role has to be one of creating platforms and forums for the decision making process and of learning how to act as true allies without obscuring the legitimate aspirations of disabled people and other disadvantaged groups.

Another important aspect of the visit to the Kosta Popov School was a planned meeting with parents of disabled children. The aim of this was to share ideas and experiences on the important role parents could play in ensuring not only good schooling for their children but the connection of their children with their local communities. We were aware that the meeting had been agreed reluctantly by the Director and he informed us dolefully that he only expected “a handful” to turn up. Having completed the tour of the school we were as surprised as the Director to find about sixty parents in the main hall, chatting and waiting patiently for a meeting with the “English visitors”. What the parents were expecting from the meeting was perhaps as unclear to them as by now it was to us. The opportunity to share experiences was inhibited by the formal setting of the room, with the parents sat in rows at the children's desks and stony-faced members of the teaching staff facing them alongside us as a sort of “panel” of experts, the whole meeting being observed by the gloomy Director.

After the formal introductions it became very clear that the aspirations and concerns of the parents for their children were similar to that of parents everywhere:

**“How can you help my son to get a job?”**  
**“How will my daughter get the supports she needs in large classes?”**  
**“How can I afford to get my child to school and back every day when I can't afford enough clothes for them?”**  
**“Why can't my child go to the local school?”**

**“How can I get the teacher to understand that my son can do things?”**

As the meeting progressed it was apparent that any real dialogue was going to be virtually impossible in this setting. The meeting was a reinforcement of the euphemism of “parents in partnership” with all the rhetoric that goes with such an illusion. The reality in fact was that whilst the parents may have some interesting comments to make it was the “professionals” and the “system” which had control over their children's lives. Whilst the questions from the parents appeared to be guarded and inhibited there was a very powerful underpinning desire to be actively involved in the education of their children. We left the meeting feeling despondent at a missed opportunity to make a meaningful connection.

The following day we made a further visit to meet some of the parents and children at the Koraci Nade Centre. This time it was us who were only expecting “a handful”, yet to our amazement the place was packed not only with parents and children from the Centre but with many of the parents we had met at the Special School. The warmth of the welcome and the desire of the parents for real conversation about important issues affecting their children, confirmed that here indeed was the grassroots reforming movement we had heard about. Here were parents and children supporting and energising each other in an atmosphere of celebration so different from the stifled air of the Special School. We shared their food, joined in their dancing and singing and wallowed unashamedly in this sudden celebrity status. The meeting at the school had been demoralising but now it seemed clearer that it had been contrived to stifle debate.

The bureaucratic principles we have referred to earlier were evidently in play here.

Chris Gathercole (North West Training and Development Team) has usefully itemised some of the characteristics that could be seen as the hallmark bureaucracy.

The bureaucrat will respond to the wishes of parents by:

- Keeping people ignorant about their rights  
**“What people don't know will not hurt them”.**
- Refusing to take risks for a service which they know is needed.  
**“It's more than my job's worth”.**
- Refusing to help people speak up about their needs.  
**“It's better not to make waves”.**

- Being reluctant to refer people to genuinely independent advocates or support networks which are promoting change and choices.  
***“These troublemakers will make things harder for us.”***
- Refusing to involve people in planning for their own needs.  
***“Experts know more about these things than you do, so leave it to us”.***
- Blaming people for their lack of progress and getting individuals to take responsibility for the systems failure.  
***“We’re doing everything we can to help you, but you refuse to do what we say”.***
- Becoming personally and professionally offended when you try to make them accountable.  
***“You should be more grateful for what we are offering you”.***
- Demonstrating an extreme resistance to change as this is seen as a threat to the continued existence of the system.  
***“We have been operating in this way for years and you are the first person to complain about this.”***
- Protecting money and resources as if it were their own.  
***“We could not possibly afford to pay for what you are asking for.”***
- Assuming that there is only one route which is fixed for all time and takes no account of individuals changing needs.  
***“We have given you this and we will review it in five years time, so don't ring us we will ring you”***

These universal features of bureaucracy can be disabling for many people who are looking for a change in attitude and practice towards their child. They are also in marked contrast to the principal of “public service” which we would argue is based upon a recognition of individuality and diversity of needs amongst the children that seek to use our education services. For example public servants, in supporting the wishes of parents and disabled children wanting to have their contributions received and their aspirations acknowledged will:

- Encourage people to be well informed about their rights  
***“The more you know what you are entitled to the more we will be able to help you.”***
- Show a willingness to take risks, in order to provide a more effective service.  
***“Even if this means upsetting some of our procedures it will improve the service we are here to provide.”***
- Encourage people to speak up for themselves and to access independent advocates and support groups.  
***“These people may be able to help you get a better deal than what is on offer at the moment.”***
- Involve people in planning for their needs.  
***“You are the expert on your own situation and your own needs.”***
- Avoid making judgements or placing blame on the individual.  
***“We do not see you as the problem but an essential part of the solution.”***
- Promote the individual's self confidence and encourage them to become better advocates for themselves and others.  
***“What you have learned about this particular situation is not only helpful to us but we can use it to the benefit of others using this service.”***
- Engage with people in an ongoing dialogue, recognising that needs change over time and that plans have to adapt to meet those changing needs.

***“If you have any further questions or the situation changes please don't hesitate to contact us.”***

- Acknowledge weaknesses and inherent barriers within the system.  
***“I recognise the system has failed you in this and that the system is unjust and needs to change. How can we make a joint argument for such a change?”***

Clearly, administration is necessary to a public service and to support progress towards inclusion. However, where accountability, accessibility, compassion and an overriding respect for the individual child are seen as less important than a respect for rules and procedures, the bureaucracy must be directly challenged and reformed. We have to ensure that disabled children achieve the right to go to their local schools with appropriate support. This philosophy of Inclusive Education can only be achieved in practice within the context of a public service ethos.

Whilst debate can be temporarily stifled, people's shared passions and convictions sooner or later declare themselves and do change the world and the way we live. Sometimes these changes come through political/legal reform, armed conflict or revolution, but often the most enduring changes occur in small, personal but nonetheless dramatic ways.

A heartening story which demonstrates this well was relayed to us by one of the parents at the Centre during the "celebration". She said that as a result of the meeting at the school, a friend of hers had found the courage to tell the Director that she no longer wanted her daughter to attend the school. Having done this immediately after the meeting, she then went to her local mainstream school and told the head teacher that her child would be coming to join them the following day. As we spoke the child was taking part in her first lessons in her local school!

Such dramatic stories are rare and issues of support must always be fully addressed to ensure confidence and success for the child and the school. Nonetheless, it is when many individuals like this mother question the "special education" bureaucracy that a dynamic for reform emerges.

The time spent in Bosnia left many powerful images and memories. It was a catalyst for reflection on the struggle of many people in our own society for the basic right to choose a decent quality of education and full participation in community life. The phrase "ethnic cleansing" may well be associated with the war in Bosnia and appear to have very little relevance to life in the U.K. After all our own "civil war" in Northern Ireland is something which too many Britons make little effort to understand and even less effort to urge politicians to address the real history and current consequences of Partition.

It is comfortable to believe, at least until another bomb detonates in a mainland city, that we have mastered the art of living together. Nonetheless we continue to label, categorise and segregate disabled children, including those with "emotional and behaviour difficulties" and exclude them from school by locking away more and more young people at an alarming and unprecedented rate. The "medical model" still seduces us into separating out, labelling and "treating" any individual who does not conform to the norm or who behaves or appears different. We may have been spared the horror of concentration camps and mass executions but we still fund and maintain the bureaucratic structures which perpetuate social exclusion and a segregated "special" education system.

It is time to listen to the voices of children and adults who have been the victims of these oppressive practices both in Bosnia and within our own islands. Time to recognise not only that any forced segregation of human beings leads directly to the death of individuals and individuality but also that belief in this practice is at the root of a dangerous and ever present fascist tendency in most of the so called "developed" nations. To have a belief in the importance of "inclusion" is not to assume some pious "correctness" which makes a good impression at interviews nor to believe we are simply up to date with good practice in Education. It demands us to directly challenge any system, political, educational or otherwise which seeks to justify the forced separation of people on the grounds that it is in "their" and "our" interests. This "us" and "them" mentality, so often seen in the thinly disguised nationalism, xenophobia and neo nazism espoused by too many "respectable" political leaders and newspaper editors, demands our unequivocal contempt. Similarly the "us" and "them" logic of segregated education must be recognised as belonging to the same tradition and deserving of the same contempt. Those who feel this is taking things too far should be reminded that the German Nazis first segregated then shot, gassed and burned tens of thousands of disabled children and adults, mentally ill people and so called "criminals" as well as millions of Jews.

We have a responsibility to ourselves and future generations to assert that whilst we remain observers to the processes of exclusion and segregation we remain guilty participants. The continuing challenge is to see that "cleansing" is an everyday practice which systematically excludes many people from life in our communities on the basis that "they" are different. Each of us has a choice in passively accepting or actively challenging this injury whatever form it takes and wherever we meet it. "Inclusion" is not a fixed destination, an end point. "Inclusion? Oh yes we did that last year but it didn't work. You have to live in the **real world** you know". It is a living

process, a striving to create new realities and ways of being with other people, whatever their background, ability, race, gender or religion. “Inclusive Education” means allowing **all** young children to learn and grow together, to learn respect and love for themselves and others and to protect each other from abuse.

If, as adults, we are willing to strive for better solutions to the world's problems and have the desire to look in the right place, we must ensure that this model of education is adopted urgently and that we start to allow young people to upset our cherished adult prejudices. In the U.K. we must continue to push for a change in the law to end Compulsory Segregation and to challenge the self-serving ideals that perpetuate the “special” school bureaucracy. The Government's recent Green Paper on special education, despite its worthy aims, is not a Charter for Inclusion, as it suggests that the fundamental issue of “Choice” will be avoided once again. There is still a long way to travel.

It is surely possible for us to grasp, at the close of the bloodiest century in the world's history, that political and educational systems which deny choice, respect and love, lead to limiting, unstable and loveless futures. If Bosnia teaches anything, it is that avoiding the challenge of inclusion will one day cost us our lives.