TREBUIE!

an organisation for children and adults with special needs Bucharest, Romania.

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TREBUIE! was founded in Bucharest in 1993 by a group of parents with children with learning disabilities together with some professionals specialising in this field. TREBUIE! means 'We ought to'. We were energised by the need to actively promote the integration of our children into the community.

Our main purpose in TREBUIE! is to ensure a 'dignified life in society' for children and adults with mental disabilities, in line with the UN Convention on Human Rights and the Rights of the Child.

TREBUIE!'s members are people with mental disabilities, their parents, friends and specialist professionals. All classes, races, religions, cultures are included. Indeed, inclusion is our main aim, to ensure that anyone, from whatever race or culture, with whatever disability, should be able to learn in a normal school and to have a workplace and access to community life like any other member of the community.

The organisation now has branches in many cities in Romania - in Bucharest, Voluntari, Braila, Sebes, Bacau, Alba and Slatina. A new branch will be developed in Navodari-Constanta. In each branch, a committee has been set up and each member has their individual responsibilities in relation to a project and its programme.

# Our Role in Education

Education was a key priority for us from the start. Families wanted their children to be able to socialise and play with other children and to have a happy childhood. In the long term, education was seen as vital for the children and young people to learn life and independence skills so that, whatever happens and wherever they live after their parents die or can no longer care for them, they will be able to live in a 'dignified and decent' way.

Initially, members of TREBUIE! met with members of other NGOs with similar aims and developed a system of a regular exchange of experience. We informed ourselves about what was happening in other parts of Romania and abroad, such as Sweden and the USA. Then we set about putting into practice what we had seen and learned: we set up a number of integration programmes:

* Day centres for children, and for teenagers;
* Vocational workshops: tailoring for girls and carpentry for boys;
* Summer camps;
* Exhibitions;
* Club activities.

# Inclusion Initiatives: School Integration Advocacy Project

The 'School Integration Advocacy Project' started with financial support from the USA. Two children were successfully integrated into a mainstream school in Bucharest. At present we have an entire class integrated in a public school in Alba branch.

An agreement was reached in July 1997 between the Central European Mental Disability Advocacy project and the central bureau of TREBUIE! We had to act quickly as the school year begins in September. A core group was formed in August. Two mothers, eager for their disabled children to be integrated in the local mainstream school had met in August to form a core group. One mother was a teacher at the school and spoke to the school principal who agreed to accept four disabled children in the first class in the school.

TREBUIE! then had to find the four children. This was not so easy because it was holiday time and many people were away from Bucharest. The core group contacted a psychiatrist, the head of a rehabilitation centre where many parents took their disabled children for play therapy and speech therapy. The psychiatrist recommended two further children and filled in the legally required medical agreement forms.

Luciana, Carmen, Denisa and Ramona were selected. These were 4 girls with different levels of disability. When the school term began, TREBUIE! members discussed the girls' placements with the teachers. Luciana and Ramona were to join one class, Carmen and Denisa were to go into another. The school Principal asked TREBUIE! to hire a social worker and two support teachers for each class. This was unusual as in Romania social workers do not normally support families with disabled children.

The teachers of both classes were a little scared. They had never had disabled children in their class before. It was a very new idea for all the people involved but with time it seemed to work out. Each child had their own unique experience. By November the teams were established. The children started to go to school, at first for only two hours each day. All four made progress, but by the end of the first year two had to drop out. Two continue to make good progress and will continue to the next class.

One child, Ramona, was withdrawn and placed in a special school nearer to her home. The distance she had to travel each day was a real problem. Denisa also had problems in class. She was very restless and excitable and other students' parents started to object to her presence in the class. This came to a head when she struck one of her classmates. The class teacher and the school principal decided that the experiment with this child had failed, even though she had made a lot of progress. She had learned to stay still for longer periods: from 15 minutes to one and a half hours at a time and she had started to learn to write. She also left the school.

Financial support for the integration project was time limited. Carmen, with mild disabilities, has made excellent progress and no longer needs her support teacher but Luciana will need support for some time to come, so her parents must seek alternative sponsorship.

# Luciana's Story - told by her mother

I had to wake Luciana early each day as the journey to and from school took over an hour each way. I had direct contact with her teachers and could discuss Luciana's progress and what I could do to support her learning at home. I was advised on activities to help her and spent two hours each day on this training.

**I felt excited when I took Luciana to school for the first time. I felt that Luciana had started an important part of her life. I felt confident that her experience would not be too negative and that nothing bad would happen to her.**

Luciana has a moderate learning disability and a speech disability. By the end of her first year she was able to learn how to read and write 15 letters and to count up to 10. By the end of her second year she was able to read syllables and to count up to 20 without any mistakes. The pace of learning is slow but with a lot of practice she is able to learn more and more. During her first year, the class had 4 different teachers - this was unfortunate and made it more difficult for her to adapt.

At the beginning all the other children wondered about what children like Luciana and Carmen could do in the class. But in time they learned to accept, help and support both their classmates. They now say that there is no difference between themselves and Luciana or Carmen! Their parents were also very supportive. They encouraged me and were very impressed by the fact that we travelled by bus for an hour to get to the school and another hour to return home!

It is an effort for me but when I see how happy Luciana is to be with her classmates and as I see her making slow progress I forget how hard it is. Luciana's teacher says it would be very difficult to have a child with disability in the class without a support teacher to work with Luciana to help her understand what is happening in the classroom.

**I know many mothers with children with disabilities who have completed their 8 years of special schooling and have not managed to learn as much as Luciana has done in only 2 years in mainstream school!**

The school principal is very pleased that she can help disabled children in her school and achieve what other countries have done for many years. She is still the only head teacher in Bucharest who permits an integration project to be developed in the school. Many heads and teachers in Bucharest still believe that the most appropriate education for children with learning disabilities is in special school. But I know many mothers with children with disabilities who have completed their 8 years of special schooling and have not managed to learn as much as Luciana has done in only 2 years in mainstream school!

After the second year, TREBUIE! had no more funding for the school integration programme as the pilot project was over, so I had to raise some more money. I was determined to continue because I saw that Luciana had made very real progress with regard to her learning and behaviour.

**As long as I have Luciana I will have hope. I hope that my daughter will continue to progress. I hope that I do not over-protect her. I hope that our efforts will have positive results. I believe that everyone needs to have HOPE.**

The struggle continues and the future is uncertain. I have managed to obtain funding for Luciana to remain at the school for the time being through Canadian sponsorship but this may only be for another year. When she is 11years old she will be required to achieve a certain level of attainment in many new subjects, each with different teachers. At 11 there are educational inspections and it is unlikely that she will be allowed to stay in mainstream! I will be forced to agree to her going to special school and I worry that she will forget what she has learned.

# Difficulties and Strategies to overcome them

The main difficulty in promoting integration is the attitude of many people and the expectation that children with learning disabilities should go to special school.

The state and local governments were not involved at all in the programme. They were invited to our round table discussions but only listened; they did nothing to promote change. During the school integration project, nothing was organised in collaboration with the national Ministry of Education. Nor does the Ministry have any models of good practice at national level.

**TREBUIE!'s main strength is the desire and determination to build a decent future for disabled children.**

**Successful strategies to counteract prejudice and discriminatory attitudes:**

* Creating a model for integration in practice;
* Lobbying local and national government;
* Positive publicity through articles in TREBUIE! magazine, seminars, use of photos etc;
* Seeking support (financial and other) throughout Romania and internationally;
* Encouraging parents to take their children out to the park and other public places.

Contact with mainstream students and their parents and publicity about the school integration project has let other people know that, even in Bucharest, a child with disability can learn at a normal school. It is now easier to lobby and to achieve school integration in small towns in Romania, than in the big city.

# Our Future Plans

TREBUIE! plans to continue to work towards school integration and to try to involve the Ministry of Education in this movement.

* We will continue to enlist support both inside and outside Romania;
* We will continue to change attitudes towards children and adults with disabilities in order to promote inclusion in the community.

# Our Advice to Other Parent Organisations

It is hard work and involves a great deal of effort but the satisfactions are also great. A child, who yesterday could not even eat with a spoon, today has learned to read, even if it has taken more time than it takes other children.

# Source of information:

We received an account of TREBUIE! and the views and experiences of a few parent members who had met together to discuss the questions we outlined. In spring 2000 the consultant was able to meet with Luciana's family while they were in the UK for a short holiday with Luciana's English pen friend!

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