



## ANNUAL REPORT 2008



Downside Up is the operating name of Downside Up Limited, a registered UK charity no.1055087, registered company no. 3026295 and of Russian Charitable Fund no. 67698

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## The Story of the Year

### *There Is Always a Second Chance*



*Stepan is two. He is sitting on a red sofa in the playing lounge at Downside Up Early Intervention Centre, cuddling his mother and smiling happily. Every Wednesday Stepan and his mother Tatiana meet here with other kids and their parents, and with the teachers Lena and Tanya. At the group sessions for children and parents, designed to prepare children for kindergartens, the kids learn to communicate with their peers and not to be afraid to act without their mothers' help. Alla or Natalia, the Centre's psychologists, will be sure to look in to say hello to Stepan and Tatiana – they helped the family to make a vital decision.*

*Stepan spent the first 8 months of his life in a home for abandoned children. In the maternity hospital he was found to have Down syndrome, and his parents were insistently advised to abandon their son to a social state institution as “having no future”. Stepan was registered as an abandoned child. In Moscow this happens in 50 out of 100 such cases like this.*

*It was a difficult decision for Tatiana and her husband, and fortunately for Stepan, not a final one. Tatiana spent several months reading all she could find about Down syndrome (the Russian-language information on Down syndrome is now abundant in the Internet). There was not a weekend when Stepan's parents did not visit him at the children's home. It was there that they learned about us – Downside Up Charitable Fund.*

*A whole new world opened for Stepan's family at Downside Up Early Intervention Centre: early education specialists willing to visit Stepan at home, psychologists ready to support the family in a difficult moment, the prospect of placement in a kindergarten, etc. And, most importantly, hundreds of other families who have also chosen to raise their very special kids, to give them love and care.*

*In the 18 months of living in his family Stepan has learned to walk, eat by himself, and has begun to speak.*

*Unfortunately, the majority of his peers affected by Down syndrome are abandoned to state institutions. Nobody will sing them a lullaby, they will never taste ice-cream or go to a zoo... Upon reaching 7 years they will be diagnosed as ineducable and will live in specialized homes till their dying day.*

*Now Tatiana has a new mission that takes an essential part of her time. It is the support of the families that find themselves in similar circumstances. We extend our gratitude to Tatiana and many other parents, for doing this together with us.*

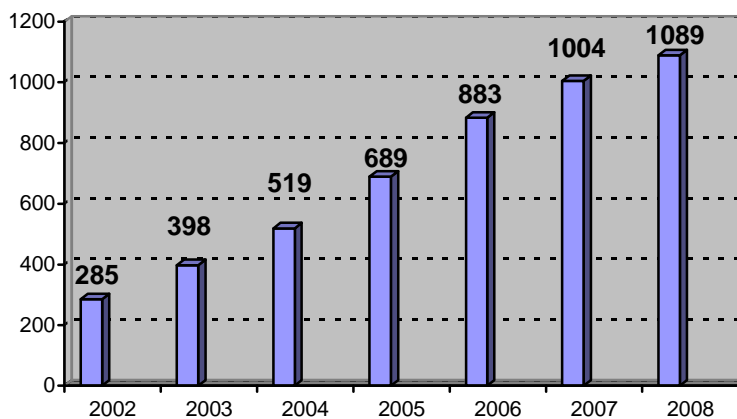
*This was just one of many other family stories –*

*Downside Up supports 1089 families*

### Early Intervention Centre

The primary goal of Downside Up Early Intervention Centre (hereinafter “DSU”) is to provide psychological and pedagogical support to the families raising children with Down syndrome from birth to 8 years. As of the end of 2008, 1089 were registered with DSU programmes, including 276 families from Moscow; 132 from Moscow region, and 681 from other Russian regions and former USSR states.

**Number of children receiving direct services**



In 2008:

- 65 Moscow families received regular consultations in their homes from early intervention specialists;
- Each week DSU held 3 social adaptation groups for 60 families with children between the ages of 18 months – 3 years;
- 4 pre-school groups were operated by DSU weekly for families with children between the ages of 3 – 7 years;
- 891 individual consultations were provided by speech therapists and specialists in cognitive, social, emotional and motor development for children over 2 years from Moscow and Moscow region;
- 248 medical consultations were held;
- 546 families from further a-field received consultations resulting in preparation of an individual long-term learning and development programme for each child;
- 68 parents regularly took part in seminars and group sessions operated by DSU psychological support service;
- 473 persons attended our seminars and meetings for parents;
- Each new family (total 333) was provided with the initial information package containing “Reading-Book for Parents”, a handbook for parents “A Child with Down syndrome”, and a brochure “Down syndrome. Facts”;
- We mailed three issues of parents’ bulletin “Take a Step” to each family-participant of DSU programmes (total 1089 families);

- At the request of professionals working with children with Down syndrome, 1300 books and brochures authored or translated by DSU, were mailed to special education organisations in Russia and former USSR states.

### **Early Intervention Centre Undertakings in 2008**

- In order to further improve psychological support of parents the Early Intervention Centre psychologists formed a local DSU psychological support unit;
- In 2008 we widened the scope of our services for the families that need assistance in the development of parent-child relationship. For families' convenience the children-parents sessions are held on Saturdays. 24 families participated in 30 such sessions in 2008;
- In 2008 our psychologists now take part in social adaptation groups to ensure higher efficiency of the group sessions. Their task is to consult the parents on their children's behaviour in a group of peers;
- A 30-days internship was held at DSU Early Intervention Centre for second year students of Moscow State Pedagogical University after Lenin. The students found out more about the practical aspects of early intervention service. They attended group sessions and learned how plan a lesson, process pedagogical documentation, compile information, etc. They also assisted DSU staff in organisation of charitable events;
- 500 on-line consultations were provided via e-mail and DSU advisory forum for parents and professionals, which recently opened on our website.

### **Early Intervention Service Achievements in 2008**

- More than 140 children with Down syndrome from Moscow are attending integrated pre-schools together with their ordinarily developing peers;
- 51 pre-schools in Moscow and Moscow region accept children with Down syndrome and use the methodological literature published by DSU in their practical work;
- 70 DSU graduates from Moscow study at schools;
- Teachers from 23 specialised and integrated schools regularly attend the training workshops run by DSU;
- DSU established contacts with all district divisions of Moscow Department for Education. The information about DSU training seminars and workshops is forwarded to Moscow educational institutions via these divisions.

*In our story Stepan regained his parents after 8-months' stay in a children's home. What is DSU doing towards having more and more children raised in their families?*

### Resource Centre

On the basis of Russian and western experience, DSU specialists have worked out and successfully implemented a **family-centered early intervention model** for children with Down syndrome. The task of the Resource Centre is to disseminate this model in Russian regions so as to make early intervention and support accessible to families in remote areas of Russia.

To accomplish this task, the Resource Centre

- publishes and circulates free of charge books, booklets, magazines and films on the subject of psychological and social support of and special teaching methods for children with Down syndrome;
- exchanges experience with non-governmental organisations in charge of children with special needs in and outside Russia;
- works on joint projects together with colleagues from Great Britain, France, the Netherlands, Spain and the USA;
- provides training to medical and educational professionals, social workers and students in Russia and CIS countries;
- holds international conferences and workshops on the prevention of social orphanhood and comprehensive support of families caring for children with Down syndrome.

### **Resource Centre Achievements in 2008**

The year of 2008 was marked by a significant advance in DSU's partnership with government institutions. Within the framework of EU project "Congenital Malformations and Genetic Abnormalities: A Comprehensive Approach to Prevention of Children's Disabilities and Social Orphanhood", an innovative model of high-risk pregnancy follow-up and support of families with disabled children was implemented in Novosibirsk region. Other important accomplishments were the establishment of **5 local early intervention centres in Novosibirsk** region, and the **adoption of backbone laws and regulations** for improvement of coordination of medical experts, educational specialists and social workers in family support.

In 2008 the Resource Centre published the first issue of its own multidisciplinary scientific and practical magazine titled "**Down Syndrome – the 21st Century**". The magazine will familiarise the Russian-speaking audience with current research both in and outside Russia in medicine, genetics, pedagogics and psychology, and the world experience in social rehabilitation and integration of individuals with Down syndrome.

In 2008 Moscow DSU partnership with Moscow Department for Education grew, as evidenced by a **joint DSU-Moscow Department action plan** incorporated into the Municipal Development Programme of Pre-school Education for 2008-2017. This will open up wider opportunities for placement of children with Down syndrome in integrated Moscow kindergartens, and for organisation of continuous pre-school teachers' professional training at DSU Early Intervention Centre.

Resource Centre experts held **35 seminars for 2500 professionals and parents** from Moscow and Moscow region, Ekaterinburg, Novosibirsk, Noyabrsk, Kazan, Vologda, Kiev, and Sevastopol. It also organised monthly traineeship at DSU for specialists from Moscow,

other Russian cities and CIS, and met with associations of disabled children's parents in Azerbaijan, Tajikistan and the Ukraine.

For the first time in DSU's history **the books** for parents and specialists authored by DSU Centre's experts, **are being translated into the Azerbaijani language and published in Azerbaijan.**

### **Publishing**

Considerable progress was made in 2008 in DSU publishing activities. All books and methodological manuals for specialists and parents produced by DSU are intended for free-of-charge circulation.

In June 2008 DSU published 1000 copies of a methodological manual called "**Logorhythmics for Children with Down Syndrome. A Parents' Guide**". Its author is Ludmila Loboda, a teacher at DSU Early Intervention Centre. The manual is supplied with a DVD displaying a logorhythmics class at DSU for children between the ages of 3-7. The manual contains a concise description of logorhythmics classes and their role in the development of speech, concentration, gross and fine motor, and coordination. It is intended for parents of children with Down syndrome of pre-school age. It may also be useful for special teachers and speech therapists who work with such children.

In September 2008 "**Reading Book for Parents**" was republished in 1500 copies. It contains a selection of articles written by Early Intervention Centre experts, and some translated foreign materials that had been published in "Take a Step" magazine for parents in 1997-2008. The articles cover a wide range of issues relating to development specifics, nursing, bringing up, and education of children with Down syndrome.

In November 2008 a brochure for specialists titled "**Motor Development of Children with Down syndrome**" was published in 1500 copies. It was prepared by a team of DSU Centre specialists: Elena Pole, Polina Zhiyanova and Tatiana Nechayeva. The brochure is based on the materials of Peter Lauteslager, a Dutch specialist, the author of a new physiotherapy method fostering motor development in young children with Down syndrome. He has cooperated with DSU for 6 years and has taught DSU specialists physiotherapeutic practices.

*Let us go back to our story. Stepan is two years old now, he goes out more and sees more and more people. It is no secret that, as a general rule, Russian society has very limited experience of communication with people with special needs. This results in many negative emotions and problems, and puts difficulties in the way of a decent life for families raising children with Down syndrome. DSU vigorously works towards raising public awareness about the nature of Down syndrome and potential of people with this chromosome abnormality in order to change attitudes in the society, so that there is more openness, understanding and acceptance towards individuals with special needs.*

### **Awareness raising Activities in 2008**

At the beginning of 2008 DSU awareness-raising project “Down syndrome: Myths and Reality” was awarded **Silver Archer, a prestigious national PR award in Russia.**

In February of 2008, DSU presented its new **exhibition project “People are just people”** in the State Kremlin Palace. It was organised in follow-up of DSU’s victory in the World Russian Peoples’ Council contest “Solutions to Social Problems”. The basic concept of the exhibition is this: each person has a singular worth and is born unique; every individual, with or without special needs, can reach his/her potential in a community which propagates and practices compassion and humanism. The exhibition offered nine stories about people with disabilities who were shown through their talents and achievements, thoughts and feelings, creativity and sport victories. The exhibition was also displayed at Na Solaynke Gallery, State Architectural Museum after Shusev, and Russian State Humanitarian University

Our awareness raising activities were very fruitful in 2008. **Over 50 TV reports were shown, 20 radio interviews were broadcasted and 100 articles were published in newspapers, magazines and on the Internet.** The stories about people with Down syndrome were shown by Channel 1, NTV, Russia, TV Centre, and published in Kommersant, Vedomosti newspapers, and Forbes, In Style, Bolshoi Gorod magazines.

Journalists themselves often ask us for material about Down syndrome now, which is a significant sign of **a growing interest for this subject and the change of attitudes.** There are less inaccuracies and discrepancies in the publications. Essentially, this theme has ceased to be “difficult” and is gradually becoming a topical subject.

Our communication with media is growing into **a mutually beneficial partnership.** For example, In Style magazine published photos from “All They Need is Love” photo calendar on 14 pages and received enormous readers’ feedback, and NTV programme One Day got the top-grate rating of the day. As the information is presented in diversified modes, the target audience is expanding. It includes artists, designers, photographers, glossy magazines audience, PR representatives and business communities.

## ***How does DSU manage to keep all its programmes free?***

### **Fundraising**

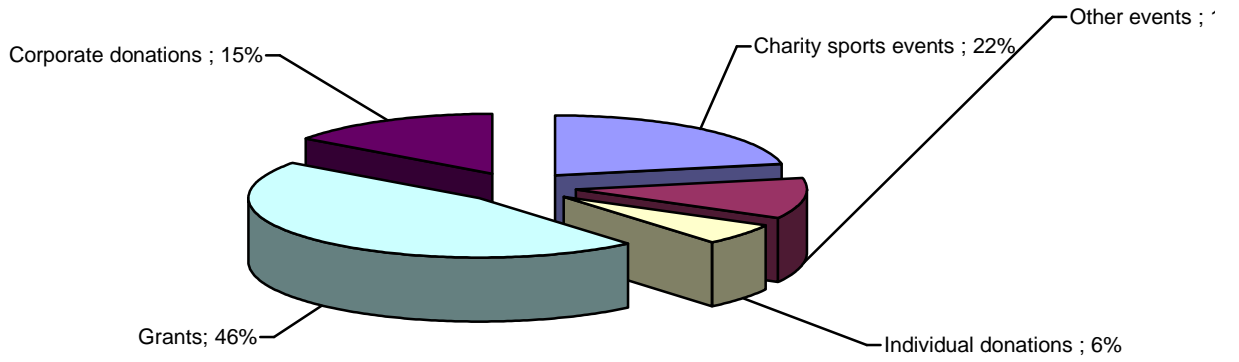
In 2008 the fundraising team of DSU maintained the good tradition of raising funds from various sources: private individuals, corporate donors, trusts and foundations. Such diversity helped us to balance the risks of losing some donors in the situation of economic crisis. Please see below the charts presenting sources of financing.

All together we raised for current activities 36 270 000 Rubles in 2008 thanks to our supporters. We spent in total 35 625 000 Rubles in 2008. All figures are calculated on the basis of consolidated accounts of UK charity Downside Up and Russian Charitable Fund Downside Up.

There were several significant achievements in our fundraising activities in 2008:

- We put additional efforts in developing individual donors' scheme by opening Downside Up Friends Club. The first Club members were registered in summer, and by the end of 2008 we raised 2 160 000 Rubles. In comparison with last year, in 2008 there were many more Russians than foreigners among those who donated individually;
- Increase in the governmental support of DSU's programmes, up to 10% of our annual budget;
- Another In-door football Tournament was added in the Charity Sports scheme by requests of corporate donors;
- A new Russian website [www.downsideup.org](http://www.downsideup.org) was opened;
- In October 2008 DSU Advisory Board had its first meeting. The goal of the Advisory Board is to help DSU by providing knowledge and business expertise in management, fundraising, PR, marketing and other issues. We aim to attract up to 20 members to the Advisory Board in 2009-2010.

### Where the money comes from



### Where the money goes

