

## INTERVIEW WITH SVETLANA MAMONOVA, FUNDRAISING MANAGER FOR PERSPEKITVY



*Interview conducted by Quentin Wodon  
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### EXCERPTS:

- “The main goals of Perspektivy are to enable individuals with severe disabilities to have a normal life, to promote their inclusion in society, and to prevent “social orphanhood” through support to families.”
- “Nobody, no matter what health problems a person may have, should be denied the opportunity to live a normal and full life. A child with developmental disabilities should be able to attend kindergarten or school. The educational system should be adapted for children with disabilities. When a person begins her adult life, s/he should have the opportunity to live in a family or an accompanying residence.”

#### **You are Fundraising manager for Perspektivy. How was the organization created and what are its aims?**

Our organization was founded 25 years ago by Margarete von der Borch, a volunteer from Germany who helped Russian children with disabilities in a St. Petersburg Child Care House (Orphanage). In 1996 Mrs Borch saw that the life of these children was full of discrimination and violation of rights, and that they lacked games, activities, integration in society, and quality medical care.

Margarete invited volunteers from Germany and Russia to join her and help children with disabilities. She brought specialists from Germany and other countries who had relevant experience to help train volunteers and Child Care House staff. Later, Perspektivy began to expand as we followed our wards from the Child Care House to facilities for adults. We also launched a Family Support Programme to assist families in raising children and adults with multiple disabilities. Today we have two Day Care Centers in St. Petersburg, a Crisis Service Center, and a Guest House. We also support St. Petersburg schools that run inclusive program for children with disabilities and we have opened three supported living projects that have become an important alternative to state facilities for people with mental and physical disabilities.

#### **Box 1: Interview Series**

**What is the mission of the Global Catholic Education website?** The site informs and connects Catholic educators globally. It provides them with data, analysis, opportunities to learn, and other resources to help them fulfill their mission with a focus on the preferential option for the poor.

**Why a series of interviews?** Interviews are a great way to share experiences in an accessible and personal way. This series will feature interviews with practitioners as well as researchers working in Catholic education, whether in a classroom, at a university, or with other organizations aiming to strengthen Catholic schools and universities.

**What is the focus of this interview?** In this interview, Svetlana Mamonova, PR and GR Director at Perspektivy in Russia, explains the aims of her organization which serves children with disabilities. She discusses some of what has been achieved and difficulties that remain.

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The main goals of Perspektivy are to enable individuals with severe disabilities to have a normal life, to promote their inclusion in society, and to prevent “social orphanhood” through support to families.



Photo: Enabling people with disabilities to live a full life.

**Working with children with disabilities is challenging. What are some of the strengths of your programs?**

We provide comprehensive support to families. We prepare children with disabilities for school in our Day Care Centers and our volunteers help them at school. When the children grow up, they can join our Adult Day Centre where they can spend the whole day taking part in different activities. If there is a crisis in a family, we take a child and an adult to our Guest House, providing accommodation for up to one month, so that the family can solve its problems or just have a break. We provide opportunities for adults to live independently in our supported living projects, accompanied by specialists of Perspektivy. Overall, we have built a working model of comprehensive support for families with disabled children. In addition, in state facilities, Perspektivy helps not only with basic care, but also with integration and socialization. Through our workshops, residents can find an interesting hobby and develop their creativity.

**What are some of the difficulties you face?**

The main difficulty is in human resources. It is difficult to find highly motivated employees and volunteers. People who work helping individuals with severe disabilities have high rates of burnout after some time. Therefore we need to monitor and prevent such situations, and support our employees, including through psychological support.

There is also no guarantee of state financing for our projects. Assisted living projects require continuous funding - they cannot be stopped if we do not find resources, since people live in these houses. In addition,

legislation does not allow the development of other approaches to improve the life of people with disabilities. For example, until now, accompanied residence has not been legally approved, a law on distributed guardianship has not been adopted, etc.

**How important has been the support of BICE for your organization and your work?**

The support of BICE has been very important. It has helped to implement projects to protect children's rights. This gives great impetus to self-development and solving problems faced by children with disabilities, thereby positively affecting their future life. In addition, BICE projects have an important coalition constituent – enabling NGOs to work and partner through a network. By working together with partners when implementing projects for children, we can achieve our goals. I highly appreciate the practice of BICE to organize seminars and conferences with the participation of other NGOs. I have attended such a meeting in Paris dedicated to the protection of children's rights. It was very interesting and important.



Photo: Providing care for young children.

**How do you understand the concept of integral human development and what does this imply for your work?**

Nobody, no matter what health problems a person may have, should be denied the opportunity to live a normal and full life. A child with severe developmental disabilities should be able to attend kindergarten or school. The educational system itself should be adapted for children with disabilities. After graduation from school, when a person begins her adult life, s/he should be able to attend day care centers and workshops, no matter how severe the disability. S/he should also be able to have some form of employment. S/he should also have the opportunity to live in a family or an accompanying residence. Any person, regardless of their developmental problems, should have a normal childhood, adolescence, and



adulthood with all necessary characteristics of these periods.



Photo: Learning music.

**Beyond the work of your organization, what is working well and what needs to be improved in terms of helping children with disabilities in Russia?**

Over the past 10 years, great changes have taken place in the Russian Federation with regards to the ratification of the Convention on the Rights of Persons with Disabilities. Russia has abandoned the stigma of considering children with disabilities as 'unteachable'. All children, regardless of their state of health, can attend school. In addition, more large cities now have accessible environments, which make life a little easier for families raising children with disabilities. We can see that rehabilitation centers and day care centers have opened in different regions. Since 2014, the home-alike atmosphere started to be implemented in state children care houses and adult facilities. Institutions began to downsize, so they gradually start to resemble a family house, where residents can enjoy socializing activities.



Photo: Arts at the Peterhof State Residential Institution.

However, there are still relatively few schools in Russia that have an accessible environment and are ready to teach children with severe disabilities. State schools try to enroll such children not in classes, but through a home-based education, which makes it impossible for such children to socialize and integrate. Currently there are no governmental models of comprehensive support for families with children with disabilities. There are few day-time care projects and private supported accommodations are also fairly rare.

**Could you share how you ended up in your current position, what was your personal journey?**

I worked in media and news agencies where I organized press conferences and roundtables on social problems. Therefore I got acquainted with NGOs that help people with multiple disabilities and learned about the problems they face. When I decided to change my professional career, I came to work at Perspektivy. I wanted to change the lives of people with disabilities for the better and help motivate the state to do this as well.

**Finally, could you share a personal anecdote about yourself, what you are passionate about?**

I really like to play football - I am a true fan. I also love to watch detective series and if asked who I would like to be, except a public figure helping people with disabilities, I would say that I would like to be a detective! In my work, a detective's instinct helps me too...



Photo: Helping adults live independently.