

## INTERVIEW WITH LOLA NASRIDDINOVA, DIRECTOR OF IRODA IN TAJIKISTAN



*Interview conducted by Quentin Wodon*

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### EXCERPTS:

- “We try to improve services and systems for children with special needs and we advocate in particular for the rights and interests of people with autism and other developmental disabilities, so that they have access to quality services appropriate for their unique needs.”
- “The support of BICE has been very important for developing and providing inclusive education and responding to the COVID-19 crisis. It has enabled us to focus on supporting vulnerable families and developing vocational trainings, while also supporting employment for girls with disabilities.”

**You are the Founder and Executive Director of IRODA. How was the organization created and what are its aims?**

IRODA is a parent’s organization for children with autism and neurodevelopment disabilities. I am a medical doctor, but also have two children with disabilities. In 2008 with other parents we created a group to try to help each other as well as new parents in overcoming barriers and find appropriate support for our children. We decided to change the paradigm towards treatment and therapy for our children from a medical model towards a social and educational approach.

IRODA’s overall purpose is to see children and adults with autism and other special needs well supported and included within local communities. We try to improve services and systems for children with special needs and we advocate in particular for the rights and interests of people with autism and other developmental disabilities, so that they have access to quality services appropriate for their unique needs. We aim to see persons with autism treated with dignity and respect, as valued members of society. The first step towards this is to see children identified at the earliest possible opportunity and their families provided with appropriate information and support.

#### 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, Lola Nasriddinova, Director of IRODA in Tajikistan, 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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Photo: Workshop with children with disability.

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

Our main strength is the joint vision of our team members that children and adolescents with autism spectrum disorders, like all children, deserve respect and recognition of their personal dignity. They deserve the right to be educated and fully included in different spheres of life (which requires access to early diagnosis, early support, and education). We recognize that the family is key above all else and that parents are the main teachers for their children and have the right to respect and understanding of their child's needs on the part of the state and society as a whole.

We are always learning and open to new approaches and methods for interventions and teaching. We have a strong team of international advisers and experts on Autism spectrum disorder (ASD) and related disorders who support us through regular trainings and meetings. We also partner with governmental organizations and are recognized by the Ministry of health and social protection and the Ministry of education which support our activities and help us achieve our aims at least in our own services, programs, and network groups. We have a national network EarlyStart which was initiated by IRODA to spread good practices based on evidence with our regional partners.

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

We have faced several difficulties. Attitudes are still not positive all over the country towards people with mental disabilities and not all programs are funded by the government, which makes it difficult to provide sustainable services and support. Tajikistan also does not have a law on Inclusive education and has not ratified the Convention on the Rights of Persons with Disabilities, which creates problems and segregation for children and

adults with mental disabilities. Finally, we still are facing with problems in terms of building our own services and trying to keep them within the mainstream educational and community governmental services.

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

The support of BICE has been very important for developing and providing inclusive education and responding to the COVID-19 crisis. It has enabled us to focus on supporting vulnerable families and developing vocational trainings, while also supporting employment for girls with disabilities and their mothers. With BICE's support, we are also helping three schools and are planning to set up parents-teachers associations in order to advocate together for inclusive education. We created a public campaign and awareness program for that.



Photo: Dancing is fun for all!

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

I understand integral human development as an universal way of thinking about people, interacting with them, and understanding others. I think that integral human development is an important concept for an inclusive community, calling for respecting and accepting everyone. For us it is a basic principle and we are employing people with neurodevelopment disabilities as an example.



Photo: Learning.

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

Most of organizational initiatives and activities are successful. We have good training programs for parents and professionals, as well as early intervention programs and adaptive education programs. We developed the first training program in the community for youth with ASD and neurodevelopmental disabilities (NDD), and set up a vocational employment center and social entrepreneurship program. We also have ongoing online programs for parents and professionals.

We need to work more on sustainable funding of inclusive education as well as tutor support, which is still not happening. Much of the focus of Government is still going to special education. We need to encourage joint advocacy efforts, including or deinstitutionalization. We wish to set up a Tutor course and continue to provide this support for children and adults with severe disability in various educational and vocational settings. As an alternative to institutionalization for people with NDD, we need to create support programs such as family group homes and individual living programs/supported living.

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

I am a medical doctor in general practice and a mother of four children. In 2008-2010 I was studying in India as part of a course on inclusion for ASD. I was working in the first early intervention center in Dushanbe. My son with ASD did not get support as services were focused on children with cerebral palsy. So we started a small initiative and a first ASD course for professionals. Our children were growing and we realized that they needed a different type of educational support and more integration. In 2011 we decided to set up our own organization and work on providing holistic services and support for young children, adolescents, and youth with ASD, NDD, and other mental disabilities. I realized that I needed to learn more on pedagogy so I did a Master's in leadership in early childhood development and education and management from Moscow Social School and Manchester University. I am still learning a lot from international experience, as well as sharing with others what I learn.

Umar, one of my sons with disabilities, is now 22 years old. He is graduating from KIMEP University in Almaty and working in a digital company. He is also an alumnus of an Erasmus exchange program. Kamol, my 19 years old son, has ASD and participates in vocational training program. They are both examples that with adequate support, children with disabilities can achieve great things. We need to provide the same chances to all children with disabilities.