

DISABLED CHILDREN

The Promise: changing the lives of disabled children in Russia

by Wendy Tabuteau

Portage - central to the work of ThePromise, a UK registered NGO - is an early intervention model designed to support the progress of pre-school children presenting delays in their overall development. First introduced in Portage, a town in Wisconsin, USA, in the 1970s the home visiting model is now used throughout the world. In the UK alone, there are 140 registered Portage services.

The aim of Portage is to support young children's overall development: their play, communication and social relationships, encouraging them to participate in the day-to-day life of their peers. Having established starting points - things the child can do now - parents and carers and their Portage worker identify what the child needs to do next to build on progress so far. Drawing on familiar games and routines of childhood, Portage uses a precision teaching approach to design a series of games and activities for the child to practise with the parent and carer each day. Each activity takes the child a tiny step towards a new developmental skill, for example:

- to give eye contact to the parent/ carer during a nursery song
- to imitate a gesture such as waving 'bye bye' to draw a circle.

In November 2002, Sarah Settelen, the founder of ThePromise, was invited to introduce Portage into the Ryazan Baby Home by its director, Tatiana Alexandrovna Gross. After a successful pilot project, developed by ThePromise in collaboration with Mollie White, a member of the evaluation team who introduced Portage into the UK in the 1970s, Portage was provided for all the children with developmental

delays in the Baby Home. Follow-up training and quality control, built into the original pilot, is a strong feature of delivery and development. In 2006, Portage was introduced to an orphanage in Yelatma, a village 160 km from Ryazan, which is home to older children with profound disabilities. ThePromise now provides Portage to 70 children in state-run orphanages in the Ryazan Oblast.

From the beginning of ThePromise's work, families and other organisations in Ryazan were involved in the monitoring processes involved in the Portage model. They acted as stakeholders, informing and involving interested parties in the Portage project taking place at the Baby Home and contributing to decisions on further development. Their role was central to the decision to set up a community project to support families caring for their children with special needs in the home. ThePromise was able to collaborate with local NGOs - Our Children, Rostock, the All Russian Society for People with Disabilities and the Rehabilitation Centre for Children with Cerebral Palsy - to identify families who might benefit from Portage. In addition, the Psychology Department of Ryazan State University was increasingly interested in Portage both through their attendance at the 2005 Portage Workshop and participation in the



Nina and George enjoying a book together. George joined the community Portage programme in November 2008 and has made significant progress with his language skills.

Portage Review Group. This led to an agreement by the University to put forward psychology and 'defectology' (special educational needs) students as volunteer community Portage workers and to allow the hours spent doing Portage to count towards the students' course work.

In May 2006 the community Portage service began with a Senior Portage Worker (Nina Davydova) and four volunteer Portage workers. Since then, ThePromise has trained 15 students in Portage and they have worked with 38 families in Ryazan. For many of the families, the weekly visit of their Portage worker is the only

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time they get non-medical support for their child. Together the Portage worker and the parent/carer are able to celebrate small successes and look to the future with optimism. Many of the Portage workers have become advocates on behalf of 'their' children, helping families to access places at kindergartens, medical support etc.

Since the first three-day Portage Workshop in September 2005, many people with an interest in children with special needs have been introduced to the concept of Portage, and over the past two years, ThePromise has been training a group of Russian trainers to be able to deliver this training in the future. ThePromise has initiated discussions with the Department for Social Protection in Ryazan with a view to getting Portage recognised and funded in state-run institutions. Getting the authorities to consider funding Portage is a slow and challenging process – this was also the case when Portage was introduced into the UK. ThePromise has developed links with potential partner organisations in Moscow, Ukraine, Belarus and Tajikistan, and works closely with Our Children, a Ryazan NGO which supports children with



Lera developing her fine motor skills. The significant progress made during her Portage sessions has meant Lera's mother and her Portage worker, Nina, have persuaded the authorities to let Lera attend mainstream school.

special needs and their families. Our Children aims to establish a Portage service from their centre in Ryazan in the near future. As ThePromise's programmes are fully established, it is hoped that this model of best practice can be replicated in other institutions and communities in Russia and the former Soviet Union.

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