

SUMMARY

ThePromise needs to raise £182,590 in 2009/2010 for its programme of work with disabled children in Russia's Ryazan Oblast.

ThePromise works to improve the lives of disabled children in Russia by promoting a system of support (Portage) for disabled children in partnership with families and carers and by encouraging a more positive attitude to disability. The programme of work includes:

- Delivering Portage sessions to 40 disabled children in Ryazan Baby Home.
- Delivering Portage sessions to 30 more profoundly disabled children in Yelatma orphanage.
- Providing a safe and interactive play room and occupational therapy for 15 older children in Yelatma orphanage
- Delivering Portage sessions to 22 families in Ryazan town.
- Developing a volunteer programme to met the wider needs of these disabled children
- Developing a centre of excellence within Ryazan to improve the lives of all disabled children in Russia

INTRODUCTION

ThePromise is a registered charity, set up in July 2003 to pioneer new ways of supporting children with disabilities in Russia, both in the community and within the current orphanage system. A hugely successful 6-month pilot project resulted in the introduction of the widely acclaimed pre-school education system called Portage into a Russian Baby Home, providing a model of best practice. Through the valuable support of individuals, companies and trusts, ThePromise has realised its initial vision and is now able to grow, meeting the needs of more disabled children in other institutions and the community, providing vital support to those who might otherwise be classified as beyond help.

BACKGROUND

Children in Russian Institutions

There are 600,000 children without parental care in Russia with at least a third living in institutions. This number is rising. Many of these children are not orphans. Their parents may have been deprived of their parental rights for a variety of reasons. It could be the social stigma attached to disability or the economic situation, both of which make it difficult for parents to care for their children. Some have simply been abandoned. Although disabled children are often placed in orphanages, many able-bodied children who enter the orphanages at a young age develop special needs purely as a result of institutionalisation.

The Orphanage System

The current system has changed little since the end of the communist era, though many professionals within it are working hard to change this and there is some visible progress. The experience of individual children may differ from the description below, but only for a lucky few.

A disabled child who enters the orphanage system at a young age will usually be cared for by the Department of Health in a Baby Home until they are four years old. At the end of this time they are assessed and classified as normal or oligophrenic, literally translated as "small-brained". Children classified as oligophrenic will receive only a minimum education and will subsequently be directed to manual jobs and denied basic rights such as to drive a car or to vote.

Some oligophrenics are further classified as "imbecile" or "idiot". These are the children with serious learning disabilities or physical disabilities. They are deemed uneducable and are sent to orphanages run by the Ministry of Labour and Social Development. Here they receive no education and minimal therapy. Conditions in these orphanages are very poor and they are closed to outsiders.

Context of ThePromise's work

Widely documented research shows that many children growing up in the orphanage system are being denied one-to-one interaction, human touch, love and access to stimulating toys – all vital to healthy emotional and physical development. As a result many of the children lack self-esteem, a sense of identity, an ability to emotionally attach to others and any sense of security. This hampers all aspects of their development and many will receive the label oligophrenic as a result of institutionalisation rather than any actual disability from birth. The 1998 Human Rights Watch report states that: *“based on independent investigations... 30 to 60 percent of orphans diagnosed as oligophrenic may be wrongly ascribed...It is difficult to overstate the significance of this examination, which for some children is a matter of life or death.”*

THEPROMISE'S RESPONSE

Portage

Central to the work of ThePromise is Portage. This pre-school education system was developed in the 1970s to support families caring for a young child with special needs and has been used successfully in countries across the world. Portage recognises the vital role played by all parents and carers in the early development of the young child. As they look after their children and respond to their needs, they remain unaware of the myriad ways in which they stimulate and support their children's progress and development. Yet they are critical. Parents and carers learn how to “talk” to the baby in ways that attract the baby's attention: smiling at the baby, moving their faces, using a singing voice until the baby responds. As children grow they look for opportunities to encourage their independence: to sit while playing, gradually withdrawing any support, later to stand independently, and to take first steps. It all seems very natural, a part of every day life.

Caring for a child with a disability requires a more systematic response from parents and carers if they are to grow and develop during their first years in the same way as their peers. Portage offers this, working with parents and carers within the familiar routines of childhood where early learning takes place, to support the child on a vital learning journey. Each tiny step in learning that the child takes on this journey moves the child towards the major milestones of early development.

The first task is to find out what the child can already do in all areas of development - social, self-help, language, movement and cognitive understanding. Having established these starting points Portage looks forward to the future, identifying the next steps in the child's developmental progress. Drawing on the familiar games and routines of childhood, the Portage worker designs a series of games and activities for the child to practise with the parent and carer each day. Each programme is tailored to meet the requirements of the individual child and activities are designed to boost the child's development in those areas where help is needed – from very early motor skills to the more complex task of using language.

The precision in the design of the activities is the critical component supporting clear communication to everyone involved with the child. It enables a range of professionals such as speech, occupational and physiotherapists to contribute to the choice and design of the teaching activities. The clarity of the targets set for the children, details of the design of each activity practised and the ongoing weekly records of their progress provide a rich source of data for sharing across professional boundaries.

Portage practitioners meet together with a supervisor or senior Portage worker on a weekly basis to share reports on children's progress, recording their successes and addressing any problems. Support provided through the supervisory structure is essentially positive. Teams operate on the basis of mutual support bringing to the discussion of any problems encountered by a child. With the benefit of their combined experience and their links with other agencies the team members are able to agree a way forward. Regular reviews, summarising each child's progress and outlining future targets for learning, are prepared by their Portage worker together with family/care staff, and relevant medical professionals for formal presentation at team meetings

Success through Portage is measured in a number of ways in particular:

- **the impact on the child's developmental progress;** recording positive change for children across a wide range of developmental starting points. Parent and carers comment on *"the sense of achievement"* *"the little steps that add up to one big thing later"* *"I can see the improvements!"*
- **the impact on the child's day to day life and experience:** reports show that the changes in the children have opened doors previously closed to them: opportunities to join in special days and social events; to participate in play with their peers and for some children to be adopted.
- **the satisfaction of parents and carers with the support offered by Portage:** reports from parent and carers show high levels of satisfaction, many commenting on the changes expressed by parents about their role *"Portage has given me confidence in my ability to help my child"*

Programme of Work

ThePromise does not condone the current system of institutionalised care in Russia and believes that the best environment in which a child with disabilities can develop to the maximum is within the family unit. However, institutionalised children also deserve loving care, therapy, and an opportunity to reach their potential and should not be ignored. Portage has traditionally been undertaken within the family setting and when ThePromise introduced Portage into Ryazan Baby Home this was pioneering work.

Ryazan Baby Home (age 0-4)

Ryazan is a large town with a population of 500,000, 180 km south east of Moscow. The town has one Baby Home. The 150 children at this Baby Home are fortunate in that it is run by a Director committed to improving the lives of the children with disabilities. Portage is now well established in the Baby Home with the wholehearted support of its Director, Tatiana Alexandrovna Gross: *"Portage radically changed the work of the Baby Home. Today I can't imagine our future life and development without using this programme"*

A team of 11 Portage workers care for the 40 disabled children. Disabilities are varied and include Downs Syndrome, Cerebral Palsy and Foetal Alcohol Syndrome but there is no disability that prevents a child benefiting from Portage. Children can reap the benefits as soon as they arrive in the home as they are immediately included in the Portage programme. The children live in family groups of around 10 children of a similar age. Many of the Portage workers are also Care workers in the orphanage and where possible, Portage workers work with children from their own group. This allows skills worked on in their daily Portage sessions to be continued in the child's group area and makes for a more realistic practise of self-help skills.

One measure of success is where the children go on leaving the Baby Home. Within the last year, 4 children have been adopted either overseas or within Russia. Adoption of a disabled child within Russia is rare, one of the main reasons being that the state provides no support for the families of disabled children. The fact they are now being adopted in-country shows just how much children are progressing and developing with the help of Portage. Adoption is the ideal outcome, but for those who are not adopted there are four other options. Penza is an orphanage for the physically disabled where they get an education. Children with mental and physical disabilities but who are mobile go to Yelatma Correctional Home where they will also get an education. Whereas in the past few disabled children from the baby home would go there, all Downs Syndrome children now go to the Correctional Home along with children with other disabilities. Eight children have moved there in the last 12 months with only one going to Yelatma Closed Orphanage, which is for children who have severe mental and physical disabilities and tend not to be mobile. Girls with special needs may go to a convent where they can remain for the rest of their lives if they so wish.

Yelatma Orphanage (age 4-18)

Yelatma is a large traditional village with wooden cottages and horse drawn carts 200 km from Ryazan. Within Yelatma is an orphanage run by the Department of Social Development and

Labour, which is closed to most outsiders. 45 severely disabled children aged four to eighteen live there, shut off from the outside world. None of them attend school. The Director of the orphanage at Yelatma heard of the progress made by children at the Ryazan Baby Home and invited ThePromise to bring Portage to the orphanage. This was a significant breakthrough for ThePromise as outsiders are not usually invited into closed orphanages.

Prior to the introduction of Portage, the children stayed in bed all day and were offered no therapy or stimulation and no education. They received their basic needs of food, clothing and a weekly bath. Following a highly successful pilot project with a small group of children in 2006, 30 children aged 4 to 15 now receive Portage from a team of 10 Portage workers. Progress has been tremendous, and the home has gone from being a silent place with empty corridors to one of noise and laughter and movement as children who have been bed bound for many years can now get themselves out of bed and move around the home interacting with each other and the staff. Many children who were only fed with a bottle in bed are now sitting up at tables feeding themselves more solid food and they are learning to play. One Portage worker said *"We thought only young children would benefit from Portage but this programme produces amazing results for older children too."*

There are a number of children in Yelatma orphanage, aged 9-17, who predominantly have learning and/or behavioural difficulties. For a number of reasons, they are not suited to the Portage programme. 12 of these children are mobile and three have lost their mobility due to the conditions they are living in and lack of stimulation. These children spend their days in a small room in the orphanage. There is no stimulation for them and they spend their days sitting or lying on padded mats. They are 'guarded' by an elderly woman who stops them physically harming themselves and makes sure they don't escape. Although there is a television constantly on in the room, it is always tuned to a channel showing Russian soap operas and this constant 'white noise' is unbearable for some of the children with sensory impairments. There is no play equipment in the room and children tend to rock and moan as a form of self-stimulation. Some are even tied up if they are a risk to themselves or others.

Working with a UK qualified Occupational Therapist, we have recruited and are training two children's workers to work with these children and develop a programme of activities for each individual child such as learning to communicate with others, going outside with an adult, drawing and jigsaws. We are also refurbishing the dayroom and have reorganised the dining room so that a corner of it can be used for quiet daytime activities, like storytelling and one to one sessions. In the summer months we are encouraging the children's workers to take the children outside – something that was never done before. The new children's workers will be trained and supported by our volunteer Occupational Therapist for a year and ThePromise will provide all necessary equipment.

Community Portage Service (age 0-11)

ThePromise believes that if more support was available in the home families would be less likely to hand their children to the State for care. In 2006, working with the Psychology and Defectology Department of Ryazan State University, ThePromise established a Community Portage Service in Ryazan. Portage is now part of the student's curriculum. 10 students, supervised by a senior portage worker, are working as voluntary Portage workers within the community helping 22 families. The student Portage workers visit each of their families once a week and work with the child and their mother on developmental exercises that can be practised daily.

The mother of one child, Sergey, said *"Portage has taught me that Cerebral Palsy is not a sentence. Sergey should be treated as special not sick. I want to continue with Portage because through this I can see that my child is developing physically and mentally"*

In March 2008, ThePromise together with the University put together a presentation on the project for an exhibition in Moscow. This resulted in an award for the best practical project that could be replicated elsewhere in Russia.

Volunteer Programme

For four months in 2007 a volunteer physiotherapist from the UK worked with children in all three projects in Ryazan oblast. She developed a programme of exercises for each individual child and worked through this with each Portage worker, integrating them into their Portage sessions by explaining how the child should be sitting or lying and introducing chairs and walkers to assist the children with their posture and movement. This has helped tremendously in the progress of many of the children. The physiotherapist now visits Ryazan two or three times a year, working with the Portage workers, checking on the children's progress and developing programmes for children new to the projects.

The volunteer programme is being expanded and we have built up a team of professionals including physiotherapists, occupational therapists and nutritionists who can all offer their expertise to help the overall development of the children. We have also organised for a number of students to visit the homes in the summer to help generally and play with the children.

A Centre of Excellence

ThePromise has shown beyond doubt that Portage helps disabled children to fulfil their potential and to lead happier more fulfilled lives. The interest and enthusiasm shown by both families and professionals in the work of ThePromise illustrates how great the need is for Portage in the Ryazan Oblast. As a result, alongside providing the Portage service, ThePromise is developing a Centre of Excellence for the Ryazan Oblast for the delivery and the training of Portage. This will be managed by Russian staff, with an on-going programme to disseminate good Portage practice more widely. This will be achieved through:

- Training Russians in Portage and training Russian trainers – from 2010 all training in Portage will be in Russian by Russian trainers.
- Translating the training materials into Russian – this will be completed by the end of 2009.
- Producing detailed evaluations of the projects with quantitative and qualitative research and continually monitoring the provision of Portage both in children's homes and in the community.
- Sharing the results of the projects with the local community, Ryazan State University and via regular Portage review group meetings.
- Disseminating the results of the project widely amongst health, social service and education officials in the region and throughout Russia.
- Attending conferences and seminars to inform relevant people about the benefits of Portage and the work of the ThePromise.
- Continuing to lobby the local authorities for improved service provision for disabled children in the Ryazan region.
- Encouraging other NGOs with different expertise who are already established in Russia to come to Ryazan and so bring a coordinated package of care to all disabled children.
- Networking with existing NGOs in Ryazan to ensure our services complement rather than duplicate each other.

ThePromise is being supported in its work by Educationalist and Portage Specialist Mollie White, a member of the original team in the 1970s, who introduced Portage to the UK *"I have been closely involved with this exciting project from the outset working with **ThePromise** to introduce Portage into Ryazan. I was certain that we would see change for every child involved, giving them a quality of life hitherto denied them. Evidence of progress, demonstrated by individual developmental gains, is recorded in our research, revealing the huge potential for change observed in every child. Their success is already challenging deep seated attitudes towards disability generating not only support for **ThePromise's** work but also valuable opportunities to promote the conditions leading to a sustainable service provision for disabled children and their families."*