



THE PROMISE

of a brighter future

The death of a child is every parents worst nightmare but one mother has used the experience to create a lasting legacy for orphaned children in Russia using a unique form of therapy, writes SUSAN SMITH

ANGELINA spent the first three years of her life bedbound, never playing with toys, and not speaking or interacting with children or adults. An autistic orphan, she was thought to have no hope of being adopted after being labelled as untreatable by staff in the Ryazan Baby Home in the Central Federal District of Russia.

But that was before a mother in a distant country made a promise to her dying four-year-old daughter that children like Angelina would not be forgotten.

When former Save the Children corporate fundraiser Sarah Settlemen's disabled daughter Ellie died she was able to use her charity experience to create a legacy for Ellie and begin what she hopes could be a revolution in the way disabled children are cared for in a country that still sees them as a burden.

There are 700,000 children, approximately half of whom have a disability living in under-resourced institutions in Russia, where they get little stimulation. The majority of these children are not orphans, but because families with disabled children are shunned by society, combined with the fact that they get little to no support from the state, many feel they do not have the choice but to put their children in institutions.

Fortunately for Angelina, she was one of the first children to benefit from Sarah's charity, The Promise. After just six months of one-to-one support, using a technique known as Portage (see box), Angelina became a bright and happy child, speaking in complete sentences and playing and laughing with other children. Just a few months later an American family fell in love with little

Angelina and adopted her.

This is just one of the happy stories to come from the tragically short life of Sarah's daughter Elbe, who was diagnosed at three months with cerebral palsy and was unable to walk, talk or see. Discovering how Portage helped her own daughter was a life changing experience for Sarah.

"We were first visited by the Portage teacher when Ellie was six months old," explains Sarah.

"With Ellie, who was very profoundly disabled, you had to be very tuned in to spot her progress. Our Portage teacher really taught us to see that with Ellie.

"I wouldn't have had a clue where to start. I wouldn't have known what to do with her, how to play with her, what the developmental steps were that I was supposed to be concentrating on.

"Nor would most people, so it was incredibly important. Ellie benefitted hugely from it, and, probably more important than that, Peter and I did as parents because we were able to see her progress."

Sadly, at the age of four, Ellie caught flu, which developed rapidly into pneumonia, and she died.

But having made the promise to help others like her, Sarah was determined to do something. She had been so impressed with the Portage technique in helping Ellie that her first step was to be trained in Portage herself. She then went to Russia to volunteer in an orphanage, where she knew disabled children were not getting the support they needed.

"The orphanage system in Russia is not very different from the one that existed in the communist era," explains Sarah. "After the fall of communism, the number of orphanages in Russia increased by over 100 per cent in the course of a decade, leaving many of them understaffed and ill-equipped to work with the children in their care."

Normally, a child who enters the Russian orphanage system at a young age will be cared for in a baby home, managed by the Ministry of Health and Social Development, until they are three years old (or four if they are disabled). They are then assessed and classified as either normal or

"oligophrenic", which literally means small-brained. Approximately half of children leaving the baby homes are given this status.

Just two months after arriving at the orphanage in Ryazan, 200km south east of Moscow, Sarah decided to set up The Promise and train local women as Portage teachers.

"The director of the baby home, who's a paediatrician, was supportive right from the word go. She didn't really understand what it was that I wanted to do, but she understood that I was passionate about it," said Sarah.

"I think it helped that we went on to adopt a little girl from the baby home, Natasha, who's got cerebral palsy. Because of that she realised that I was committed to these children and that I knew what I was talking about and she was prepared to let me give it a go."

Initially six women were able to work with 24 children, including Angelina, and they saw dramatic results. In just six months many of the children showed significant signs of accelerated development, developed self-help skills, started walking and their communications skills improved. The director of Ryazan orphanage was won over.

Word of the success at Ryazan spread, and a pilot programme at a home for older disabled orphans in the same district started.

In an archaic caste-like system, after leaving the baby home, "oligophrenic" children receive only a



THE PROMISE IN ACTION: (left) Sarah hugs her daughter Ellie, who died in 2000, and to whom she made the promise to help other disabled children; (top) Sarah with Roman and Sveta at the Ryazan Baby Home; (above) Sarah playing with other children in the orphanage; (right) a Portage teacher works with a young boy in the Ryazan Baby Home.

minimal education and are expected to grow up to take on manual jobs and are denied rights such as being able to drive a car or vote. Even worse, some "oligophrenics" are further classified as "imbecile" or "idiot". These are the children with serious learning disabilities or physical disabilities. They are deemed uneducatable and are sent to orphanages for the disabled 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 most are closed to outsiders, including the Yelatma orphanage where The Promise began working.

When the charity arrived in June 2006, there were 47 severely disabled children aged from four to 18 living at Yelatma Orphanage and looked after by five nurses. They lived in small rooms, each containing 10 cots or small metal beds. The children spent all day in bed, had no therapy or stimulation, and were not allowed to attend school.

"The Yelatma orphanage was very keen from the beginning," said Sarah. "Even though the situation was so appalling and they had so much to be ashamed of, they were really brave and allowed us in."

The pilot project involved nine children, up to the age of eight. These children showed such amazing progress in six months that in September 2007 the programme was extended to all bed-bound disabled children.

The Promise is now growing in influence in central Russia. As more orphanages hear about it and

the Portage system it promotes, more and more are interested in getting involved. However, The Promise is concentrating now on persuading the local authority in the Central Federation District, to take over the support of the Portage workers before moving to other local areas.

It is also because of the inroads the system is making into societal attitudes through a community-based programme that Sarah is optimistic that this can be a reality.

With the support of Ryazan State University, the community portage service currently has 20 portage teachers.

"The community project in Ryazan is incredibly important because it models the kind of support we have here," explains Sarah. "It is really important that everything we benefitted from as parents, Russian parents get too. Not just for their own benefit, but also partly because it's a preventative measure and a tool to try and help families stay together so they don't end up handing their children over to the institutions. Unless that support is in place there will be a continued flood of children to the orphanages."

Setting up a charity like The Promise has not always been easy, but for Sarah is her personal responsibility to Ellie. She has been able to use her professional experience to create something that is deeply important to her.

"I wasn't really aware to begin with the impact

that my experience at had on The Promise," she acknowledged. "But I had imbibed all of the principles of Save the Children's working model out in the field, and I understood how important it was that everything we did had to be sustainable and everything had to be owned by the Russians.

"If I hadn't had that background I'm not sure that all of those principles would have come so naturally - the fact that at some point in the future it would be nice if The Promise worked itself out of existence."

In the meantime there is a long way to go to both help the children in Russian orphanages and ensure that families get the support they need. The immediate challenge is one that Sarah is familiar with, fundraising. The Promise has set itself a target for 2008 to raise £150,000 - an amount being spent every 35 minutes between now on 2012 on the London Olympics.

With this The Promise can train and support 30 portage teachers to help turn around the lives of 90 children. With this amount every year it can transform the attitudes of Russian people, and the lives of disabled children across the whole country.

WANT TO KNOW MORE?

View videos of The Promise's work in Russia at:

www.thepromise.org.uk

PORTAGE: *what is it?*



Portage is an educational system aimed principally at pre-school children with special needs: it provides the children with one-to-one support and also provides help for their families.

The first such scheme was developed in Portage, Wisconsin, USA in the early 1970's to meet the needs of the young children living in rural communities. Since its introduction in the UK, the success of the approach has led to an increasing number of services being developed nationally. There are now 140 services registered with the National Portage Association in Britain.

The aim of Portage is to support the development of young children's play, communication and relationships and to encourage full participation in day-to-day life within the family and beyond the home. Portage services are committed to securing inclusion in the wider community for all children and families in their own right. Support offered through Portage is based on the principle that parents are the key figures in the care and development of their child and Portage aims to help parents to be confident in this role whatever their child's needs may be.

In order to do this the Portage home visitor works alongside parents offering practical help and ideas to: make learning fun for all the family; encourage a child's interests; and address problematic situations.

The Promise has transferred the principles of Portage to the orphanages in Russia, where although parents are not involved it has seen tremendous results.

Despite the fact that it is traditionally focused on pre-school children, The Promise has discovered it can have a dramatic impact on older children and teenagers who have had little developmental support or stimulation during their lives.

After the six month pilot in the Yelatma Orphanage, which homes children from four to 18 years old, some children had seen their developmental progress improved by eight times.

Twelve-year-old Nastya is one such example. The pretty little girl has cerebral palsy and learning disabilities. Living at the Yelatma Orphanage, she would lie in bed all day, unable to do anything for herself and with no stimulation.

Since the introduction of Portage in Yelatma in June 2006, Nastya has responded really well and can now sit independently and walk holding an adult's hand. She enjoys being in the play pen with other children while she takes in what is going on around her in the room.

She has learned to feed herself and drink from a cup and is now able to eat in the dining room with the other children.

She also enjoys exploring toys and is particularly keen on anything that makes a noise: her special favourite is a bell bracelet, which she likes to hear jingle. Noises make her smile, which is the best reward of all.