

My Promise To Ellie

It's every mother's nightmare to lose a child, but Sarah has made sure that her special little girl has left behind a wonderful legacy

After my daughter's death in January 2000, I whispered a promise to Ellie that her life would not have been in vain," says Sarah Settelen.

"Ellie was profoundly disabled with a complex range of problems, complicated further by constant epilepsy. Before she died, just before her fourth birthday, I'd read about a similarly disabled little girl of the same age who lived in a Russian orphanage. Shunned by the outside world, she stayed in her cot the entire day, was never picked up and was never loved.

"It struck a huge chord with me and it was the image of that poor little soul that propelled me to Russia a couple of years later. I just had to go before I could get on with the rest of my life so, accompanied by my friend Iona, I went to work in an orphanage for babies.

"There is a massive stigma associated with disability in Russia. Families with disabled

children find that they can't cope. Social services provision is very poor and if a family is struggling, for whatever reason, the first course of action will be to remove the child and place it in an institution. Numbers of institutionalised children are rising and there are insufficient funds going into preventative

children, meant they were herded around together between beds, potties and tables.

"Toys were only brought out if there was a visitor there. Four-year-old disabled children who couldn't walk would be sent to children's orphanages, where they would be bed-bound until the age of eighteen. After

Ellie, met so many of the children's needs. The system helps disabled children progress more quickly through the key developmental stages and can be applied to all levels of disability. And this is how, via a charity I have named The Promise, I am thrilled to say that we are now helping children

Shunned by the outside world, these little ones were never picked up, never loved

care and social support.

"My visit left me horrified by many things; a system in which initially healthy young children are condemned to a life of behavioural and developmental problems because they have no one-to-one care or stimulation. The low numbers of staff, who were so preoccupied with basic activities such as washing or cleaning that they did not interact with the

that they'd be herded off to adult institutions, assuming they had managed to survive that long. It all touched me very acutely.

"Then, towards the end of our two-month visit, it suddenly occurred to me that the Portage developmental education system, which we had found to be a fantastic learning tool with

and their families via three projects in the Ryazan region, 100 miles south east of Moscow.

"In the baby home I'd first visited we now have Russian Portage workers producing fantastic results with all the disabled children there. Attitudes have changed, with staff in the home now completely committed to these kids. And we also have ten Portage workers practising with



A kiss
for Ellie

Cynical staff have been transformed and now see the potential of these children

the older disabled children too.

"Before, many of them were losing the will to live because they were bed-bound and isolated. Now, under the care of our workers, they are walking, doing puzzles, they are being taught how to get dressed... they are just flourishing. The formerly cynical staff have been transformed too and now see the potential of these children.

"We also fund a community project where Portage workers make weekly visits to family homes. The more support we can give them there, the less likely it will be that those family units will break down and the child will end up in an institution, so it is a vitally important preventative approach.

"With all three projects we hope to demonstrate a model of

good practice which will encourage the local government to take on the funding of these services and replicate our efforts in different regions.

"One unexpected result of all this is my daughter Natasha. On my first day in Russia in the baby home we made an instant connection. I was drawn to her like a magnet. My husband and I adopted this feisty, strong-spirited, determined little child whose future was going to be so terribly bleak. She is now ten years old and doing really well.

"If they could, every bereaved mother in the world would want to create a tribute to their child. My wonderful Ellie has left this life-changing legacy for so many other children. In the work of ThePromise she will never be forgotten."

Make ThePromise A Reality

There are currently around 700,000 children living in institutions in Russia, including disabled children abandoned by their parents because of the social stigma and economic difficulties their disabilities bring.

ThePromise aims to raise funds to train skilled workers to help these children via three projects in Russia.

Their work focuses on Portage, an educational system aimed mainly at pre-school children with special needs, providing



For Russian children with special needs

each child with one-to-one support and also giving help and support to their families. ThePromise relies on donations to train and support these workers. To help contact ThePromise at www.thepromise.org.uk or call 020 8737 2987. Visit the National Portage Association at www.portage.org.uk for more information.