

PEOPLE'S CHAMPION

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One mum's hard work and dedication to support her Down's syndrome child has offered a lifeline to other parents in north London



The People's Champion –
Lucy Newham with son Leo

Discovering your child has Down's syndrome can be an experience fraught with anxiety and questions. But rather than dwelling on the situation, Lucy was determined to move forward and do the best she could for her youngest son. Having waded through a vast amount of information, she discovered Leo's main difficulties would be developing speech and language. But a search for a local service or project that could help proved fruitless.

"There was nothing out there, nowhere to go," Lucy says. "It was so frustrating."

Through a friend Lucy discovered and joined forces with a fledgling project for Down's syndrome children, as it was then, run from one of

the parent's front room – Downright Excellent.

Juggling life as a parent of two young children, Lucy set to work. Late nights ploughing through a mountain of paperwork at her kitchen table soon became a part of her routine, but together with her skills as a trained solicitor and her 'can do' attitude, Lucy established Downright Excellent as a registered charity to take it to the next level.

COMMUNICATION

The project now provides educational therapy for 30 children and their families,

and is based at the Prior Weston School's Golden Lane campus in Islington, north London. Through work with speech and language therapists, the children learn a form of sign language called Makaton and play games to improve short-term memory and muscle tone in their mouths and tongues.

"The biggest challenge for Leo and all children with Down's syndrome is acquiring language – signed and spoken – that others can understand," Lucy explains.

"Communication is so important – within the family, at nursery and at school, and in the wider community.

"The work we do with the children means they are much better equipped to start mainstream school. Some of them even start school with a higher reading age than the other children!"

Lucy is positive about the future. "Children with Down's syndrome are capable of a lot more than people think

Speech and language therapists help develop communication skills



and, with the right educational support, can go on to achieve great things, which is what we all want for our children in the end. Parents of children with Down's syndrome are no different." **BIG**



JENNY AND MAX, AGED 4

"I've been a trustee at the project since it started in May 2005, so I've seen it develop and I've witnessed the huge difference it makes to many families, including my own. The therapists here are so good. Max has made a real improvement to his speech and he can now join words together and say them a lot more clearly. People can understand him, whereas before I always had to translate for him."



Did you know...?

- ▶ Down's syndrome is caused by the presence of an extra chromosome in a baby's cells. It occurs by chance at conception and is irreversible.
- ▶ Around one in every 1,000 babies born in the UK will have Down's syndrome.
- ▶ There are 60,000 people in the UK with the condition.

Source: Down's syndrome Association



LILIAN AND ROBBIE, AGED 6

"I was at such a low point, having been turned down by a Down's syndrome support group after my son Robbie had been on the waiting list for almost a year. It left me devastated. Robbie hadn't had any speech or language therapy and I was concerned he was falling further and further behind.

"When I visited Downright Excellent, it was the first time I really felt that someone cared about what happened to my child. I felt so supported and now we come religiously every week – it really is my lifeline!"

What BIG did

Downright Excellent was awarded a grant of £26,860 in 2008 to extend and improve the speech and language therapy sessions for children with Down's syndrome.

Find out more at www.downrightexcellent.org



PAULINE AND JAN, AGED 3

"As soon as I sat down at my first Downright Excellent session, I knew I'd found the place that could give my son Jan what he needs. We've now been coming here for two years.

"Jan gets the opportunity to mix with an appropriate peer group, which I think is really important for him. It's also so important for us parents as well because we provide support for each other and give each other advice and share experiences."

A fresh start



Nyssa puts the finishing touches to her new flat

Nyssa was only 15 when she first visited West Lancashire Crisis and Information Centre, determined to give up her destructive lifestyle and start anew

Nyssa's stomach flipped as she stepped into the kitchen, packed with young people chattering and jostling to make tea.

She was terrified but knew the centre was her only chance to turn her back on alcohol and drugs and plan for a better life.

Today, the 18-year-old has her own place, a job and qualifications – a far cry from the troubled teenager she once was.

Nyssa moved into the centre aged 16 because of major issues at home. She was regularly abusing alcohol and other substances, her life spiralling out of control.

"I got in with the wrong crowd and started drinking," she explains quietly. "I thought I was streetwise and unstoppable, but looking back I was just too young to be on the streets."

Once at the centre, it didn't take long for her to settle down. It was there she met Mike, who had a real influence on her life and later became her boyfriend. "Mike told me it was him or the drugs; I chose him."

Senior support worker Laura noticed a difference. "Nyssa was like a different person," she says. "It is wonderful to see

someone respond so well given the right support and the right environment."

After just eight months, Nyssa had moved into her own flat, got a job at a children's play centre and enrolled in college. She now has a BTEC qualification in IT and is currently studying childcare.

"The Crisis Centre helped me so much," says Nyssa. "If it wasn't for them, I don't know what would have become of me – they helped me save myself." **BIG**

What BIG did

West Lancashire Crisis and Information Centre is home to the Lottery-funded Building Lives project, which was awarded £468,804 in March 2007. The money helped fund two self-contained flats to help young people develop the skills and confidence to live independently before being assisted to their own accommodation.

PHOTOGRAPHY: DOMINIC HOLDEN