

Sharing knowledge helps

Deborah Gundle talks about her self-styled 'mumsnet for special needs' and how other parents are the key to making the community site work

When my oldest son Zach was born, I knew instinctively that something wasn't right. At seven months old, he was diagnosed with Angelman syndrome, which meant he'd grow up with profound learning disabilities.

Looking back, I wish I'd asked for more help from my family and friends in those early years, because I know now they would have been happy to give it. It's often hard for other people to help, unless you tell them exactly what they can do.

One of the things I struggled with when Zach was little was how much time and energy I'd spend solving day-to-day problems. Zach was still crawling till he was about seven, and I spent ages trying different things to protect his knees, which were always rough and bruised. Finally I hit on the perfect solution – goalkeeper trousers for kids, which were padded in all the right places. But Zach was nearly six by then and I couldn't help wishing I'd known earlier.

That's how the idea for Netbuddy came about. It would have been so helpful to have some sort of practical handbook, with tips and ideas for all the problems I encountered when Zach was growing up. But of course nothing like that existed. I knew other people had probably solved the same problems I was dealing with, and I wished I had access to their knowledge.

Health visitors and professionals were, of course helpful, but unless you have direct experience of learning disability – unless you're living with it day-to-day, you can't really know what it's like.

I launched www.Netbuddy.org.uk two years ago with the aim of capturing that huge wealth of expertise that parents and carers have, and making it easily available for other people to tap in to. I wanted



■ Deborah Gundle, far right, with Linda Goldberg, of Netbuddy, Samantha Cameron and Ben Robertson, who has learning disabilities

to create a place where people could submit and search for tips on a whole range of practical issues – everything from bed-wetting to coping with challenging behaviour.

Of course, when you're a parent to someone with special needs, caring doesn't end when they become an adult. So Netbuddy offers tips for people of all ages. Zach is 18 now, and he's going through one of the most important stages of his life – the transition from children's to adults' services. I value any advice I can get from other parents who have already been through this process.

That's what Netbuddy is all about – passing on what you have learned to others who can benefit from it.

Helping each other

Netbuddy works because people in the learning disability community want to help each other. If they can offer some support or advice that will make someone else's journey easier, they will.

I am delighted by how quickly the site has taken off, and by the strength of the community we have already developed at Netbuddy. But in some respects I'm not surprised by it because Netbuddy fills a very basic need for practical problem-solving that everybody has.

We've had people writing in telling

us that a tip they've picked up on Netbuddy has changed their lives. Sometimes it can be a really simple idea, but it might have given them their first full night's sleep in 10 years or provided the breakthrough in toilet training they'd been desperate for.

Netbuddy has also hit a chord with professionals – teachers, nurses, therapists, support workers – who come into contact with people with learning disabilities through their work. They use the site to pick up tips and ideas for themselves, but also to pass on to families they support.

Last month, Samantha Cameron hosted a reception for Netbuddy at Downing Street. She described Netbuddy as a "vital resource" for families who are affected by learning disability. It was wonderful to have that recognition, not just from someone so high-profile, but also from another parent. Having had a child with special needs herself, she really understood how important Netbuddy was.

It does feel like we've come a long way very quickly, but we still want to reach a lot more families and carers who could benefit from using Netbuddy. As parents, we have a goldmine of useful information at our fingertips, and it's up to us to pass it on.

■ www.netbuddy.org.uk

NETBUDDY TIPS FOR MAKING CHRISTMAS SPECIAL

■ Talk to family members ahead of time. Discuss your child's needs, and ask for their support. Let them know this will make the whole experience better for everyone.

■ Foil is an excellent wrapping paper. It is very sensory and makes presents easy to open.

■ Plan ahead: I always give my two ASD children "jobs" to do at Christmas, like taking coats or offering nibbles round. Giving them something to do reduces their stress of having people in the house. I also give them an itinerary so they understand, for example, that people stand around

and chat a lot, and that is part of the occasion.

■ If your child is not keen on opening "unfamiliar" presents, wrap up some old favourite toys as Christmas presents. Opening something familiar can be very reassuring.

■ Print off a week to view calendar page – from your PC or the internet and add a picture of your planned activities during the Christmas hols (divide into morning, lunch afternoon etc) and this will help put your child at ease about the plans for the week.

■ Add cinnamon to your child's playdough to

gradually introduce the new smells. One thing that people with autism complain about the most during Christmas is the many different perfume smells coming from visiting adults – ask your family and friends to hold off on the perfume.

■ Create a "safe place": Leave one room in the house, possibly your child's room, free from anything to do with Christmas, so he/she can come back to the room as a "safe place" if he/she needs to.

■ Spread out the presents: Our son gets overwhelmed if he has to open all his presents on Christmas Day. We find it much easier

to allow him a few gifts at a time throughout the Christmas period.

■ Our daughter loves looking at pictures so we've made a Christmas book with pictures of her and the family doing things at Christmas. We've included pictures of the tree, her in the school play, us all putting up decorations, etc. It helps her not to get overwhelmed with what's going on.

■ Stay calm! If your child reacts badly to stress, staying relaxed and low-key over the Christmas period is one of the best things you can do to keep your child's behaviour in line.