

Point of view: parent

The loneliness of parents

Judith Hooper describes the sometimes heart-breaking reality of bringing up a child with SEN

We are at a party. The children are running around, just this side of chaos. My daughter Rose holds my hand, wobbly on her feet. If I let go, she will fall. The other parents stand together, chatting and smiling over their cups of tea. But Rose is happy by the pond, so there we are, on our own.

We are on a steam train in the country park, waiting to depart. As the driver passes our carriage, I sign to my daughter, saying clearly "Man walking" – no more than two words, the speech therapist has said. We are in the two-word club. The other families are in the full-sentence club. We haven't got entry to that yet. The door's shut.

Being the parent of a child who doesn't fit can have an unexpected consequence: you don't fit either. As other mums celebrated their babies' milestones, I waited and, eventually, I realised I was waiting alone. I didn't know, until it happened to me, how lonely that place could be. The fact that anyone walks or talks is, I now know, a miracle. And it is a miracle which most parents take for granted. But if your child can't share in it, you cannot enter that world either, and you are standing on the other side of an invisible door.

There were, thankfully, those who reached across the threshold – people for whom that door of separation didn't matter quite so much: the mum who noticed us stuck in the corner and would

bring over a cup of tea and stay for a chat, or the neighbour to whom I would turn after particularly painful encounters with medical professionals. But at times, the feeling of being separate, of leading a life that others couldn't quite understand, would overcome me, and there came a point when something was cracking inside me. My husband told other mothers how I was feeling and things started to shift. There were

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knocks on the door. We received an offer of a weekly babysit, so that we could go for an evening walk together. A few people – enough, though – reached out.

The lonely moments still happen. That threshold between their world and ours is still there, and probably always will be, but we feel the separation less acutely these days. For right or wrong, this is partly because, little by little, our daughter has, like a flower opening in slow motion, gradually, painfully and joyfully moved into a place that is more bearable to the world – that causes

less fear, and confusion. No longer dependent entirely on the support of an adult to get around, she can now walk on even ground with a frame or sticks, and is beginning to explore independent walking. She can talk, not entirely comprehensibly to others but she is striving all the time to express herself. I no longer need to spend all my time organising appointments and contacting therapists, and have emerged into something that feels like sunlight, like an animal reaching the end of hibernation. And I have developed a close friendship with another mother whose children have a disability. Thanks to her, I now have companionship. That shadowy door is known to her too, and that in itself is a comfort.

The fact is that every human being knows what it is to feel loss. It is sometimes hard to admit it, but if your child is disabled or has a chronic illness, you – the parents – have suffered a loss of the life you expected to have as a family, of the ability to take health or developmental milestones for granted, and of the assumption that your child will grow up and fly the nest and do their own thing. It is the loss, dare I say, of normality. Your perspective on everything is altered and nothing is quite the same again. Some people can go there with you and some people can't. Thank goodness for those who can. **SEN**