Simon Baron-Cohen: My special sister Suzie

I have two special sisters but today is Suzie's day. She touched everyone who met her with her kindness, gentleness, and humour.

She was born in London on June 29th 1961, with a medical condition called Sturge Weber's Syndrome. It was clear she was not a well baby, having epilepsy. She needed full time caring and nursing. She wasn't developing in the expected way and my parents, a young beautiful couple, were emotionally devastated that she would never be the daughter they expected.

In 1961 there was little understanding of the effects on parents of having a child with severe disabilities, so they were not offered any support. Instead, the paediatrician told them that for the sake of the older two boys, Dan and me, she should be sent away to a children's home. So at the age of two, she left our little family. That's why many of you never met her. The doctors also told my parents Suzie wouldn't survive beyond age 15 years old. They were wrong about this, and they were wrong to send her away.

I was 5 years old and Dan was 6. My parents and my brother and I had already formed a strong attachment to her, which was suddenly severed. But there it was: In 1963, she went to live in a nursing home in Bognor Regis in Sussex. On Sundays we would drive down to see her, and take her for walks in the pram as if she was still a baby, even though she was a child who couldn't yet sit up. We'd go watch the cricket in the very English village green. We would stop at Box Hill on the way there and Dan and I would roll down the hill and get an ice cream at the bottom.

Sending Suzie away was part of a Victorian mentality towards disability that was based on "out of sight, out of mind". But that meant she was not part of daily family life, even though in fact she remained central to the emotional life of both of my parents and my family. My younger brother Ash and sister Liz were born when she was already away from the family, and grew up hearing about a sister they hardly knew.

When she was 10 years old, in 1971, we were told that Suzie would be moved to a hospital for what was then called 'mental handicap'. She was moved to Harperbury Hospital near Radlett in Hertfordshire. These enormous wards on the outskirts of London were meant to be pioneering. It was part of a societal belief that 'asylums' were safe havens of peace, removing the vulnerable from staring eyes and discrimination towards those with disabilities.

Moving to Harperbury had a second big impact on me and my siblings, because the hospital policy was that children under 18 years old were not allowed into the wards in case they found disability frightening. It was true that on those wards, people would shout and scream, they looked very different, some with hydrocephalus for example, with very large heads. They would come up and touch you or grab you because they lacked normal communication skills. The doctors in their wisdom judged such an environment was too frightening for young children.

So my parents continued to visit most Sundays but us kids lost complete touch with Suzie.

Ten years later: In 1981 I graduated from university and went to work in a small unit for kids with autism, just 20 minutes from where Suzie was living. I decided I couldn’t work with these kids if I couldn’t also face any childhood fears I might have about Suzie and disability. I didn’t believe Suzie or disability was frightening, but the message society had given me all through my teens was that disability had to be locked away. Out of sight, out of mind.

So one day, after work I took the school minibus and drove into Harperbury Hospital. I was an adult now, age 22, so no doctor could stop me. It was my right to see my sister. My heart was beating fast, as I walked to her ward to find her. Would she know me, her brother she hadn’t seen for 10 whole years?

The reunion with Suzie was one of the most special days of my life. She was beautiful. She had the most amazing warm eyes, she had my mother’s big smile, she had long golden hair, and she sat in her wheel chair, beaming. She had no audible words, only some small phrases.

I kissed her and held her hand and although she couldn't talk, we connected emotionally. I took her out for a walk in her wheelchair and talked to her like any brother and sister would chat. The only difference was I did all the talking and she smiled and made soothing sounds, and I had no idea how much she might understand. I told her stories about the family and about you all. And I felt whole again, like connecting with a twin I had and lost and re-found.

After that I visited regularly, on my own. I found what made her laugh, which was mostly slapstick humour. Making a funny sound or dropping a teddy bear from a great height would send her into peals of laughter. I found the care staff loved working with her because of her sunny personality, her love of music and jokes. There was nothing to be frightened of, only someone to enjoy being with. And I’m sorry for each of you who didn’t get that chance to hang out with her.

And as I got reacquainted with her again, I no longer saw her disability. All I saw was the person, in all her beauty and emotional warmth. Her disability just melted into the background and became irrelevant, because I was focusing on different, more meaningful aspects of her.

When my kids Sam, Kate, and Robin were born, they also came to visit her in Harperbury, even as babies, with my wife Bridget. The doctors banned me and my siblings, but I wasn't going to let them repeat that for the next generation.

The ward staff loved seeing little toddlers climbing on her lap on the wheelchair, playing with her stuffed toys, tickling her, and Suzie giggling and giggling and giggling. They loved to see my kids as they got a bit older deciding it was fun to push her in her wheelchair as fast as they could, racing around corners, one riding on the back whilst the other pushed, with Suzie laughing and laughing and having great fun. And they loved the calmer moments when I would get out my guitar, and we’d play blues music or folk songs or Jewish melodies and we’d all be sitting around her wheelchair, singing and clapping and dancing.

My kids would get to visit with their grandparents when they saw Suzie too, so that Suzie became the hostess, bringing the generations together. Whereas my mother used to find visits to Suzie full of sadness, she grew to look forward to them as wonderful tea parties with cake and singing and telling family stories, getting up to date, and Suzie was the princess in the middle of all this hustle and bustle of family life.

If the doctors had sent her away from the family, Suzie magnetically attracted the family back to her, and we looked forward to our visits as the highlight of every month.

In the 1990s society finally woke up to what they had done to generations of people with disabilities, people like Suzie, excluding them from society, and they introduced a concept called ‘normalization’, itself philosophically problematic. The good part was the government closed the long-stay institutions and tens of thousands of people like Suzie had to be relocated into “care in the community”.

My father was very worried about where Suzie would be placed, and he was right to be. “Care in the community” turned often out to simply be the private sector making money out of disability, with agency nurses and no proper care. Our family visits continued every month, to a small care home with different staff each visit, and we had a real concern that quality of care was being sacrificed.

In 2002, Suzie had her next big move, to Ely, near Cambridge, in a home run by the Sue Ryder charity, partly because we had to get her out of the private sector, and partly so she could be closer to me as my parents were getting older. My father had been Suzie’s advocate all of her life, talking for her at social services meetings where decisions were being made about her, but at a certain point he asked me to take over this role, which I was more than happy to do. It gave me more reasons to visit with Suzie and allowed me to get involved in the detail of her life, her daily needs.

In Ely she lived in the Old Bishop’s Palace, next to the Cathedral, and I enjoyed the sweet irony that a woman in her forties with no language and with profound learning disabilities lived in a beautiful old palace. My parents still came up from London every month and we came over from Cambridge, and there was music and laughter and Suzie was always in the centre of our family gatherings, which my kids looked forward to with enormous pleasure. They loved their aunt and she clearly loved them. The Bishop’s Palace had the most amazing garden, and we would walk with Suzie in the wheelchair through the garden, watching the ducks, singing and chatting to her and her chuckling away.

When the Sue Ryder home closed because the charity ran out of money, I found her a home in Fen Road in Cambridge, just 10 minutes from my house, a most wonderful housing association charity for just 6 residents. Unlike her previous homes where the nurses wore uniforms, in Fen Road the nurses wore jeans and t-shirts. They played with Suzie and their other residents just like we as family did. They larked around and kibitzed and she responded with laughter, making their work so rewarding. These staff didn’t work for the money - they are the lowest paid in our society. They simply love their work and they loved Suzie. And Suzie loved them.

They gave Suzie a great 50th birthday party 2 years ago, when my sister Liz, her husband Alexis, their children Shayna and Kobi, my brothers Dan from Brazil and Ash from LA and all the family came up. There was a band playing in the garden, and Suzie again was the queen of the party. She beamed at everyone, drew them towards her with her warm eyes, which twinkled with kindness, and she still giggled with happiness if anyone provided any slapstick. She was the Queen of Slapstick.

In Cambridge, I would regularly walk with her, just the two of us, or with the family, along the tow path along the River Cam, in good weather or in windy weather, and she loved to watch the boats going past, seeing life, and feeling part of a community. She went on holiday to Center Parcs with her carers, even to Paris, went to the pantomime or to musicals at the Corn Exchange in Cambridge. She was finally part of a community. The old Victorian mentality of exclusion and been replaced by a modern approach of inclusion, of acceptance of disability as part of diversity, of respect for difference, and the end of stigmatization.

Suzie lived through all of these revolutions in how society views people with disabilities. If she had been born today she would have been supported to stay at home, and you would all have seen her as much as you see the rest of the family.

Just 9 days ago she developed pneumonia, and because she had become weak because of feeding difficulties she was unable to fight it. The family came to see her in Addenbrooke's Hospital last Sunday, kissed her and held her hand and stroked her hair. My father sat with her every day last week, coming up and down from London to Cambridge to sing to her, but now she was too weak to join in. Her carers from Fen Road came every day to the hospital too. My youngest son Robin in Thailand, when he heard the news that Suzie had passed away, cried with me on Skype. He too was so attached to her.

Let me finish: Suzie taught me 4 important things in life. First, that you can be happy with absolutely nothing materially. She radiated happiness and in that sense I know she had a good quality of life.

Second, that no matter what life throws at you, you can keep your sense of humour and laugh your way through it. Every visit with her I came away happier than I arrived, and buoyed up. She had that special quality.

Third, you can have a deep relationship without words, even without concepts, just by being with another person, holding hands, and connecting.

And finally, social policies can try to divide a parent from their child, or a brother and sister from each other, but they won't succeed. The love is too strong.

Suzie taught us more than we taught her, and our lives were richer for having shared the journey with her.

Professor Simon Baron-Cohen is director of the Autism Research Centre, Cambridge University. To donate to Hebrew University research into Sturge-Weber Syndrome and related conditions, please go to http://www.bfhu.org/donate/ where there is a drop-down menu including Susannah Baron Cohen's name

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