

At Last, Lisa!

"Well at last, Lisa. We always knew there was something we wanted to do but you never let us in!" It was these words from her sister, Margie, that made Lisa realise how successfully she had kept friends and family at arms length in all the years since her daughter Hannah was born. "All those wasted years", she said to her husband that night. "I never realised that Margie has been thinking like that."

Lisa and Michael had always believed that Hannah was their responsibility alone. She was their child and, despite the difficulties inherent in living with a daughter with quite complex disabilities, they had managed their lives well. They both had strong, connected families. Hannah and their older son Jacob, were very much a part of everything that happened in their extended family life. But Lisa and Michael had never asked family or friends to help out in any way; nor had they talked over any of the fears or concerns they had about Hannah or her future. It was only now, when Hannah had only two more years left at school, that they had begun to worry about what would happen next for her and for them.

Lisa knew parents who had formed circles of support, groups that met regularly to talk through matters to do with their child's disability; matters to do with school or with the medical profession or just to share ideas about how to make life better for their son or daughter and to think a bit about the future. She and Michael had talked about this idea and, although they appreciated the theory of involving other people in their thinking and planning, they could never quite bring themselves to ask anyone else to be involved at that level of their life. "Everyone else is busy with their own lives. And we know we can always call on the family if anything dramatic happens";

But they both had a growing concern about what would happen for Hannah when school finished, or if she and Michael "fell under the proverbial truck" at the same time. Lisa eventually talked things over with a friend who worked with other families who had sons and daughters with disability. Anne again suggested the idea of gathering a few people together. Friends, family, anyone who showed an interest in Hannah and who seemed to have a positive idea about what her life could look like. The idea was not to form an ongoing support circle but simply to invite people for a conversation or brainstorm session that she would facilitate. "Two heads are better than one," she said, "and it doesn't hurt for people to know a bit more about Hannah and what she needs every day for her life to work well. They see that Hannah lives a good life now but no one really knows what you do to make that happen so how could they really be of any help if anything dramatic happened to you?"

And that was how Margie finally managed to tell her sister what she had always been thinking. How could anyone break through the barrier of perfection that Lisa and Michael presented to the world? How could they be more involved in Hannah's life when they could see ways to do this but not how to make it happen? How could they broach the subject without suggesting that they were offering charity? The group planning session gave Margie, and the other family and friends who came along, a way to be involved, at least in the thinking about Hannah's life. Margie said that the more formal setting and the fact that there was a facilitator to guide the discussion seemed to give her permission to talk openly and in a safe, non-confronting way to Lisa and Michael.

There was nothing dramatic or immediately life changing that happened as a result of the meeting but both Lisa and Michael were quite overwhelmed at how much their friends and family had obviously been thinking about Hannah, and about them, over many years.

"I had no idea that they knew so much about Hannah. And they saw her in different ways...not just as a young child like we do...Jake was amazing...a real big brother in how he sees Hannah and what he wants for her...it's good to have everyone on board...even just a bit...I feel that I can talk to many of them now about things...and we could even gather the group together again if we needed to talk about anything major. There were some good ideas about what might work for Hannah now and maybe if we saw that bus coming around the corner we would feel a bit more secure about Hannah's future."

(Names in this true story have been changed.)

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