

## **An individual budget in practice**

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*This is a personal account of how one family moved from being passive recipients of care to being “in control”. Anticipating the expansion of such schemes with the forthcoming White Paper, the account explains the mechanics of an individual budget enabling self-directed care.*

Our first child, Joseph, was born in October 1988. Like many families, we started to make the huge adjustments needed with the demands that such a small person brings. Our life was ordinary until six months later when Joseph contracted meningococcal meningitis. To cut a long story short, after numerous assessments and examinations, it was evident that Joseph had severe developmental delay and we entered a world we never knew existed – Service Land. And so our journey changed – we were suddenly parachuted into a very strange and scary place. In this world of Service Land, lots of other people became involved in our daily lives, constantly making recommendations to do this or do that. And all the time you seemed to have to ask for permission just to live an ordinary life.

But our life was certainly not ordinary. To function as a family, we needed lots of support from other people, especially when Joseph’s sister Rosie and his brother Jacob were born. Joseph you see finds it really difficult to sit still, he doesn’t use words to communicate and his body doesn’t always do the things he wants it to; in fact many people have said he is “extremely challenging.”

So, as a family, we have needed help, but the help we received was what I call “conveyor belt care.” This means that services put in help at the most crucial parts of the day based on their assessment of our needs. For example, home care was provided by the Local Authority to come into the home and assist with getting Joe bathed, dressed and eating his breakfast, and then there was more help again at tea time. At first it worked okay but, as the service increased because of Joe’s support needs, we needed two people to assist him. In the end, it began to feel that we were being invaded every morning and every tea time by an army of home care assistants. Due to rotas, rest days and everything else, the number of different people coming through our door had gone from two to over 40 in six months. This was totally unacceptable for Joe and very intrusive for us as a family. But all the time we felt that we had to be eternally grateful for the ‘gift’ of professional services that didn’t really work.

Not only did Joe’s home care not work but he was also being sent to a school that was over an hour’s drive away. Joe wasn’t happy there and his connection with his community was getting weaker by the day. And it was all at a phenomenal cost to the Education Department. Joseph didn’t need specialist out-of-borough support; he just needed people to listen to what he was trying to say in his own unique way.

So, when we heard about '*In Control*', we jumped at the chance of being involved. We had felt over the years that we were passive recipients of a service system that intruded into our lives and confused Joe. What he really needed was a person-centred approach to his support — in other words it was designed for Joe, by Joe and the people who knew him best. He also needed to be recognised as an equal citizen, someone with rights who was entitled to his own life, but someone who was also prepared to take on some responsibilities too.

We started to help ourselves by organising a circle of friends for Joe. The circle consisted of people who loved and cared about Joe and other people who were paid to be in his life. The Social Worker also came and used its meetings as a starting point for his assessment. At the circle meeting, we discussed Joe's dreams and visions for the future, what his skills and gifts were, a step-by-step approach to how he was going to get there and who we needed to involve.

The social worker used the assessment to give Joe an allocation of money from Social Services and we considered a number of the other funding streams that might be available to Joe. In short, we applied for funding from the Independent Living Fund (ILF) and we maximised Joe's benefits. It is essential that the individual maximises their benefits, for in order to get a life you need some money to spend – a disposable income.

This first phase of money enabled Joe to employ four Personal Assistants (PAs) [we need four as he requires two people at any one time to support him] who work on a rotational basis and enable Joe to access ordinary social and leisure opportunities. For instance, he now attends a gym, goes on the treadmill and swims in the pool. This enables him to access an ordinary facility, meet new people, have some important exercise which helps him to sleep. We get an excellent package from the local gym for they allow any of his PAs to go with him. He visits a lot of the National Trust Parks as he is interested in history and likes to walk round the gardens. He loves fairs and fast rides. He also likes to ride his bike, which is a specialised tandem. His PAs need the right range of skills to support him in his varied life style and we also need the flexibility from the PAs so that, if we go away for a weekend, they can continue to work together as a team and they can stop-over at our house to support Joe round the clock.

The management for the staff works relatively easily: I do a monthly rota, the PAs fill in timesheets and they get paid on a monthly basis. I have a local company of accountants doing the PAYE and it all works quite smoothly. We have insurance for the PAs and have to deal with any staff management issues, which so far has worked fine for us all. Over the past few weeks we have started to break down the funding within the education system and have enabled Joe to attend the local college. We have considered how he can be in control of all of his week. So what does it look like now?

- He now goes to college four days per week which is funded by the Learning and Skills Council and he has his own PAs working with him within the college. Currently, they are paid by the college for this element of their work.
- To get to college, no more taxis and escorts – he catches the bus like other young people and his PAs come to the house and support him from here to college. The walk to and from the bus stops assist him in having a calmer day in college. This is funded by the Local Education Authority (LEA).
- After college, he goes on to the gym which is funded from his original social and leisure resource allocation from ILF and SSD.
- On his fifth day when not in college he is doing some voluntary work. This has only just started and we are trying out a few different things. This is currently being paid for (the support) by the LEA until SSD do a reassessment.
- His weekends and evenings are the same as in the first instance with the funding streams being ILF and SSD.

It sounds complicated but, in the whole scheme of things, it isn't and, in comparison to the difficulties around the support in our lives before Joe got in control, it is so much better for the whole family. Joe has consistency with the people supporting him within his whole week – people he has chosen to be there. The support is flexible and works around what Joe needs to do, so if he has a dental appointment he just fits it into his life, just like the rest of us do, instead of his Dad or I having to take a half-day off work to travel over an hour each way to pick him up! There are also many times when Joe doesn't have paid support and we are really happy as a family to support him at this time and it is so much easier because he has been active and has had a fulfilling day.

So how will it move on in the future? We are setting up a trust as Joe turns 18 and the trust will manage the staff team and will have the legal responsibility for managing the finances. The trust will be people who love and care about Joe, and it will be developed so it is sustainable, as we, his parents, get older. After all, I never wanted to be his care manager, his accountant or his director of services – all I ever wanted to be is just Joe's Mum - bring on the washing!