

# Stephen's Story

The first person to receive an Individual Budget in Worcestershire, in October last year was David Wood, on behalf of his son, Stephen. David describes his story here and we have been delighted to be able to work with David to get Individual Budgets off the ground. The journey, as David describes, has not been an easy one, but it has led to some really positive changes and has paved the way for others to follow suit.



This is Stephen's story. It all started some 20 years or so ago when my wife and I decided that we wanted to adopt a 6 year old little boy with Special Needs. We travelled to London to meet Stephen and, over the following weeks and months we got to know him and then, after the adoption formalities were completed he became our son and joined our other son to complete our family. From that day our life changed as we embarked on what turned out to be a roller coaster of emotions and battles with the "system" to try to ensure that Stephen was able to integrate into the community and lead as normal a life as possible.

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Stephen has Cerebral Palsy, Learning Disabilities and Challenging Behaviour. He can walk (although he sometimes uses a wheelchair) he can talk, he has a roguish sense of humour he is a sociable young man and he is a whiz in the kitchen. Oh and if you want good service in a restaurant he can, as they say, charm the ducks off the water, so he chats the waitresses up and they fall over themselves to serve him.

Before Stephen came into our lives we knew nothing about Challenging Behaviour, very little about Cerebral Palsy and very little about learning disabilities (except from our other son who is dyslexic) but goodness me how quickly we learnt.

I don't like the words Challenging Behaviour because it conjures up a picture of someone who is not "acceptable" to society. We quickly learnt that whenever Stephen

"challenged" it was, more often than not, as a result of someone in the system misreading the signals that Stephen was giving out or, more likely, totally mishandling the situation.

Stephen went to a local Special School and then, after nine years and as he approached adulthood, he was expelled because, as they put it, it was an inappropriate place for him to be.

When he eventually moved into Adult Services the problem didn't go away - if anything it got somewhat worse. For example he isn't allowed to drink Cocoa Cola because the caffeine in the drink makes him "high". Someone in an Adult Services Day Care Centre decided that, as an adult, the "system" decreed that he should have "freedom of choice" - allowed him to drink Cocoa Cola with the result that he completely trashed the place.

The "system" then decided that the best way to manage Stephen was to take him "out and about" rather than have him stuck in a building all day. However after conducting a risk assessment the "system" decided that this could only be achieved if he was accompanied everywhere by three (yes three) carers - just in case he kicked off.

In the midst of all this along came a care worker who decided to stick her neck out and work with Stephen on a one to one basis. As time went on she established a close bond with Stephen so much so that she took him to College (where he learnt to cook). She has looked after him in our house while we have gone abroad for a well earned break. She has integrated him into her own family (he gets on very well with her young daughter). She has also introduced him to other carers who, like her, are confident enough to work with him on a one to one basis.

Over the years that she and the other carers have looked after him there have been times when he has been "difficult" but throughout they have maintained a continuity of behaviour management and, above all, they have valued him and respected him as an individual.

While this was going on Stephen was still accessing the "system". He was still attending a Day Centre, still having respite services because his carers could only work with him (paid by ILF funding)

at weekends and evenings to give us a break. It soon became apparent however that my carer's way of working with Stephen and the "systems" way of working with him were completely different. The "systems" way of working with him was bogged down by "red tape" whereas the ILF carer's system was more flexible and gave Stephen, in effect, more choices as to who he wanted to be with and where he wanted to go.

Then along came Person Centred Planning - where the system is made to fit the person rather than the other way round. In order to be part of this we filled in endless forms wasted endless hours meeting with professionals to what end? Stephen, because of his complex needs, was going to cost a lot of money and, surprise surprise, there wasn't enough money in the kitty to provide a service that would meet his needs.

While this was going on Stephen was still going, daily, to his Day Centre, still attending his respite unit and still accessing the community with his ILF worker - oh and he was still, of course, living at home.

Eventually we got to hear about individual budgets and In Control. A system which seemed much more flexible and much more user friendly than anything that had gone before.

This new system, on the face of it, put Stephen back in the driving seat, back in control of his own life and his own destiny.

Currently he is still accessing his Day Care services for three days per week but the other two days he spends with his care worker who is working to the new system. He goes to college and he has joined an activity group where he can play football, basketball or just chill out if he wants too.

He still has his moments still sometimes gets frustrated (don't we all) but on the whole his challenging behaviour has diminished and he seems much more compliant and in control of his day to day situation.

So what of the future. Our dream is that Stephen will live in his own house with his own staff looking after him and that he will be in control of what he does.

That's Stephen's story - he is still here large as life, still charming the ducks off the water and still, occasionally asserting himself just to make certain that everybody knows that he is still here and wants to be heard and accepted by those around him.

*“he is still here large as life, still charming the ducks off the water”*

