A friend from Shropshire told me, that at a meeting to discuss Personalisation and Individual Budgets. One parent protested “It would be no good giving my son an individual budget; he would just spend it on what he wanted”. I was amused by this tale but have since given that statement due consideration and have pondered how I would have responded. On a ‘hopeful day’ I would have been at pains to point out that this was indeed the whole purpose of Personalisation and that it would bring exciting and promising changes in the delivery of services. I would then have used those words that readily trip of everyone’s tongue, as I told her “It will give Choice and Control to the service user”. However, on a fearful day, I might be more tempted to simply reply “Chance would be a fine thing!”

So what is it that makes the days different? Why is it that I still feel uneasy and uncertain at times about something I believe in with a passion and desperately want to see succeed?
I have two daughters; Zoe is 30 and has both learning and physical disabilities. Jane is 25 and works as a support worker. Just like any other parent, their health, happiness and well being, has been and always will be paramount, and for both of them my greatest wish would always be that their lives would be happy, secure and fulfilled. Two, very different sisters, two, very different lives but my desire as their mum to see they have the best life possible is the same for both of them. The difference lies in how that is achieved. Jane is able to make her own decisions, right or wrong, she seizes opportunities, takes a few risks, make her own choices in life, comes and goes more or less as she pleases, in fact within reason, does what she wants, basically she is able to get on with her life and enjoy it. It’s different for Zoe.

Zoe’s life began on Christmas Eve 1979. Immediately the support system that I have been so grateful for and so dependent upon swung into action. Family and medical personnel first, joined over the years that followed by people from education, therapists of all descriptions, until eventually Adult Social Care claimed her at the magical age of 19. I say magical, because I often wondered if that is how they perceived that birthday, as suddenly, many services and opportunities that had been available throughout her schooldays just disappeared. It was, as if at 19, all was well or perhaps as good as it would get.

Time to accept life as it was for Zoe and get on with it and to my shame that is what I did. Zoe entered the Day Centre. I felt we had made it, reached our destination, and achieved our goal. An hour’s ride on the white minibus in the morning, a day spent safely within the walls of the centre before the same white minibus returned her home to me in the evening. What more could I ask for?

Over the next few years Zoe became Queen of the jigsaw. Her ‘home book’ has, I think, the word jigsaw written on every page. There were other activities but for whatever reason jigsaws became the default for Zoe, all day and every day. Still I did not question it, I remained grateful.

Fast forward now to 2007, we have all been rocked by the scandal of Budock Hospital and there are rumours that the day centres will close. It’s time to wake up.
And that’s exactly what I did. Through the help of the brilliant and inspiring family led courses of Sharing Knowledge and Partners in Policymaking, that are now run by ‘In Control’, I gained and learnt so much. I became aware of opportunities for Zoe and for the first time learned to value my role as Zoe’s mother, to truly believe that no-one knows more than I do what is needed to make her life as good as it can be and to be confident in that belief. At last, with the help of others, I had seen the need for change and with their support and encouragement I could clearly see a different and better way forwards.

Zoe has been in receipt of ILF for 18 months now. Her life has changed dramatically. No longer the Jigsaw Supremo, she is supported by 3 PA’s and is more able to access the community and belong to it. Life has expanded for her; it has greater meaning, more opportunities. What could be better?

Well... an individual budget, so we’re told and this is where my hopes and fears lie. Without a shadow of a doubt this is what I believe is the way forward, not just for my daughter but for everyone. Personalised budgets, the ability to choose, the luxury of choice, the opportunities, the freedom, it’s an exciting concept, it’s a right and it is what I want, but... I have to feel confident. I have to be sure that life will not only be better then, but will continue to be for the rest of Zoe’s life. I need to know that it will be sustainable, and most importantly, I need to know it will be set up and delivered properly, fairly, and by confident people who believe in the concept just as much as I do.

I have been involved with Cornwall’s pilot project for the last 12 months, I have sat on the steering committee, and the Champions group and I can tell you, fears won hands down over hopes, during that time. Zoe was on the pilot scheme, she has her indicative RAS; we were set to go but the triumph of fear over hope, the realisation that I had no confidence in the people or the project caused me to call a halt, and withdraw her from the pilot. Zoe’s life is built on trust, her trust in me is everything, for that to work I must trust the people or systems that shape her life. I didn’t and couldn’t, so we could not go on. From the relief I felt I knew I had made the right decision but the disappointment was immense. I felt let down and
angry and resentful that all the hours I had spent helping to further Personalisation had been wasted.

Cornwall will tell you that lessons have been learned and I hope that’s true but I’ve heard that phrase before. So I would like to take the opportunity to say what I, as a parent, need to see to really believe this path is the right one for that great future I want for my daughter. I don’t imagine I am the only parent with these desires, anymore than I imagine Cornwall is the only County experiencing problems, so I’ll just say, if the cap fits...

I know that some people who work in services find the changes difficult but if they don’t believe in the future or feel threatened by it, they should look for a new career, now is not the time to be half hearted or to harbour doubts.

Right now there needs to be strong leadership and all need to know that they are being led.

We must see in those leaders, inventiveness, imagination, belief and determination, as well as a very clear understanding and feel for the route that must be taken. Outcomes will be best if everyone across the services works together, valuing and recognizing each other’s roles and contribution and acknowledging the need for flexibility and mutual support.

‘Putting People First’ states clearly the need to develop and increase social capital. Opportunities must be sought and developed. Community is the key to the success and desired outcomes of Personalisation. We are all aware of the difficult times we live in. There has never been a greater need for building good relationships with the community, where difference is welcomed and everyone feels a valued contributor. However, at the same time that inclusion is sought, so too is the Police check, the risk assessment and all the protocols which make, would be friends and supporters step away. Risks and opportunities or opportunities and risks cannot be separated.

Good communications are vital but I am concerned that in an age so dependent on electronic methods, people have become more remote from each other, social networking is more and more confined and the social skills of engaging with others are being lost.
This leaves a sad gap in all our lives but how much bigger the gap for those who, for whatever reason, already have difficulty with communication.

So I hope we can go forward with:

Strong family leadership and true recognition of its power and value.

Training for Personal Assistants and recognition of the importance and value of their role.

PA banks.

Easy access to reliable brokerage and increased opportunities.

Strong, creative, imaginative leaders of services who are prepared to look forward with belief and hold on to that vision.

Elected members being educated by self advocates and families in what is needed from them, to ensure better outcomes, sustainable futures and for them to recognise their accountability.

Recognition that if ALL work together, that includes, Health, Social Care, Local Government, family carers, paid carers, self advocacy groups, and the voluntary sector; we can begin to value each other and see individual contributions, be they ideas or actions, succeed and have the desired outcomes.

Connect with and learn from other regions and organisations, especially what works well. Look at what is working already and use those who have “seen the light” to help the momentum to gather pace towards better practice.

Be prepared to take a few risks, make a few mistakes, ADMIT THEM, learn from them and move on with greater strength and purpose!

And above all else, make sure that in each of us, whether we be parents, paid or unpaid carers, those who use services or work within them, there is always an abundance of hopes and dreams so that eventually, everyone will have real choice and control, that Zoe’s life becomes more akin to that of her sister and the young man in Shropshire really can spend the money on what he wants!
Then and only then will his mother, this mum standing here and countless others throughout the country know what Personalisation really means. For, it will only be when we personally witness the changes in the lives of those we love and care about, and feel the impact on our own lives and those of our families that it will have true meaning.

*Margaret Upham*