Being at the Centre of My Life

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I thought I was in control of my life once and I was for a while. I utilised a service known for its high standard of person-centredness for about five years. However a change of management and the subsequent erosion of organisational values led to deterioration of the delivery of service.

The illusion of person-centredness persisted in that all written material continued to state that I was the employer and I was still encouraged to think I was in control. However I discovered that the managers and staff of the service I was using were having meetings about me without me. The tasks that I instructed the workers to do were ignored. Workers did what they 'thought' I needed to have done. As a result my health suffered because things were left not tended to despite numerous requests. Workers went away from my home with preconceived ideas and unfounded perceptions about my life and my friends that were not only none of their business; they were harmful to me and to my friends' reputations.

I exited myself from that service and it was during that process that all my fears were confirmed. The service providers did everything in their power to punish me for my decision and undermine my abilities and to diminish my reputation and confidence. So much for being in control!

I am always keen to learn from the things that do not work or that go wrong. I began thinking: how was I going to use what I was learning? What could I do to bring to my life the kind of supports I actually wanted in a way that allowed me to be me, totally? These questions have led me on an exciting and powerful journey and have made a number of things very clear.

I am the only person at the centre of my world. Anyone who believes they put me at the centre of their thinking has misconceptions about their role in my life. There are too many competing factors. It is impossible to put someone else completely at the centre of one's life, without one's own needs impacting on the other person. The needs of the service also compete with the needs of the individual. The amount of support provided is based on budget formulae, the culture of an organisation and its ability to attract and nurture good people. It is unrealistic to think that I or other people who use such services could be at the centre of things. Too often the needs of the service and staff come to be valued more than the person themselves.

It became clearer to me that the reason I encountered such empty words and inadequate support was because I was being perceived as my disability. My needs were merely related to the needs of my disability. However I am not my disability – I am Lisa first. In reality I simply need some assistance with a few parts of my life. It is not complicated, nor would I want it to be. A significant step in living my life the way I want has been thinking about what I need and want separately from the perception of needs my disability creates, and then breaking these into easily identifiable roles. For example, I need help with my housework so now I

employ a cleaner. I found her in the Yellow Pages and she is a professional. She is not employed by any disability service; in fact I am probably the only person with a disability who she cleans for.

Likewise I need help with my personal hygiene; this need also is now met through the employment of professional nursing staff. Both the nurse and the cleaner are very clear about their roles and do not try to take over other aspects of my life. They do not have a need or the opportunity to meet or discuss me – I am not at centre of their existence nor would they ever pretend that I am.

When I contrast this with what I was receiving from my previous 'disability support workers' the picture is dramatically different. They saw their role as overarching my entire life. They did not really want to clean my home, they did not see that as being their role, yet clearly that was what I employed them for, and what I needed and expected from them.

I am grateful for the lessons which have contributed to the way I live my life now. Without these insights I would still be treated, done to, and done for in my own home. I now know the difference between good service and bad has nothing to do with you being at the centre, it is totally based on how much you are valued and respected. I know I have an equally respectful relationship with all the people who play a supporting role in my life. Without this, person-centredness is an empty phrase. I am now back in control of my life, and my destiny is mine once again. This is true person-centredness to me.