

family

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Abstract

This article describes the struggle of June Maelzer, an English woman who has cerebral palsy and needs 24 hour care, to live independently with real freedom, choice and self-respect. Her first flat was the result of help from friends and a precarious support system. After years of pressuring for funding to assist people who have disabilities to live independently, she now reaps the benefits and lives with her partner and son in her own home. It entails a lot of ongoing hard work to organise the support required and should never be taken for granted.

Keyword: Individualisation

LIVING IN THE REAL WORLD

Individual funding allows June Maelzer to live independently. She has real freedom, choice and self-respect. But it was a hard struggle to achieve, as she explained to David Brandon.

JUNE Maelzer is effectively the dynamic and positive director of a small unit of an individual social services department in Burnage, Manchester. In her proper work, she is a training officer for Manchester City Council, responsible for recruitment and selection training. Because she has very restricted movement stemming from cerebral palsy at birth, she spends most of the time whizzing around the city in a specially adapted electric wheelchair.

At home, she appoints and employs four fulltime staff whose job is to look after her. "They have to do everything for me. They get me up in the morning, wash and dress me, get the breakfast, do the housekeeping, cooking and cleaning and help me with food. They take me to work and take dictation, write memos, help to answer the phone."

Such independence comes after many years of long hard struggle with a long succession of au pairs and Community Service Volunteers. She studied for a degree in psychology. "I didn't do so well academically because I spent too much time at late night parties." That experience was followed up by a Diploma of Youth and Community Work and a year at Woodbrooke College in Birmingham.

She has an impressive track record in voluntary work. For several years, she worked for Lifeline, the well known Manchester based drugs project. She spent nights at The Boot in Birmingham, a night shelter for young homeless people. She even ran a club for Hells Angels!

On starting at Manchester University in the 1970s, there was a struggle with the various authorities, including the Spastics Society, because she wanted to live independently and not in a 'home'. Friends helped her get a flat and money from her grant and the Spastics Society went towards a succession of au pairs - rather a precarious support system.

After getting a university degree in psychology and her diploma in youth work, it was still difficult to get paid work because of her physical handicaps. She was working as an Open University tutor when her son Frankie was born in 1976. She was involved in a variety of Manchester based pressure groups like Access, Housing and Disability and the Disability Forum, of which she was a founder member.

She tutored in the psychology of women at Manchester Polytechnic in 1984 and in the following year got her present training job. Around this time

she was pressuring with a group of friends for a Centre for Independent Living (CIL) for people with disabilities. "We were trying to get a base funded

June Maelzer: 'The trust doesn't mean living happily ever after but it does mean independence and freedom from interference.'

to help people get support, counselling and advice. I never thought it could apply to me because I needed 24 hours a day care and it would be too expensive. I was being looked after by Community Service Volunteers at that time. But friends bullied me and although the CIL never got funded, after years of pressure in 1985 we got £30,000 a year for my personal support, index linked, from mainstream money through the social services department."

In the first year the money was laundered through a local Housing Association. "It didn't really work because although they were employing my staff, I was doing the recruitment and appointments but couldn't sack anyone."

In the following year, a formal trust was established with four trustees which included June and three friends. A friendly

accountant helps out. Money is paid directly into the trust's account. The annual amount is calculated on the basis of the number of hours care that June needs, on an agreed hourly rate. There is no legal agreement between the trust and the City of Manchester Council. It would cost the authority considerably more to care for June in a home.

The trust meets every six weeks, more often if there are specific difficulties. June advertises for staff in local newspapers and does all the interviewing—a

busman's holiday! The staff are mostly young women who stay between nine and twelve months on average.

"Compared with a council home, I have got complete independence of petty rules. I've got a responsible and interesting job. I've got a family. I live with my partner and our son. I live in the real world. Living in a council home, as opposed to my own house, would mean no real freedom; no choice; no self respect; having to do what staff told me to do. However, it is hard

work organising it all. Doing the rotas and managing the staff is hard work - to do what other people just take for granted.

"We take employees on three months' trial. I am looking for flexibility; an easy going nature; fun loving; sensitivity and a driving licence, because we travel around everywhere in our old adapted taxi. The trust doesn't mean living happily ever after but it does mean independence and freedom from interference."