

# Being BOSS is best

Anne Pridmore and Steven Rose consider how individuals who employ their own staff can achieve freedom and independence

For many people with disabilities the option of hiring and firing their own staff has technically been possible since the Direct Payments Act was passed in 1996. Initially, only tiny numbers opted to take this route and, of those, just a fraction had learning disabilities. But even in 1996 a few pioneering disabled people were already employing personal assistants (PAs) and some had been doing so for a number of years (see Anne's story below).

In 2006, a decade after the Direct Payments Act was passed, there were just 60 people with a personal budget. Today, according to the Centre for Welfare Reform, there are some 12,000 people with a personal budget, plus a further 70,000 receiving a direct payment. While the recent rise in numbers is impressive, there remain 1.3 million people yet to receive a personal budget.

Nonetheless, there is a sharp and increasing rise in the number of disabled people employing PAs, bringing significant benefits and implications for employers and employees alike.

## Anne Pridmore: my journey to freedom

I believe that people with learning disabilities, their families and supporters who are considering employing PAs, could avoid 'reinventing the wheel' by learning from physically disabled people like me who have been employing PAs for many years.

One of my first experiences of indirect services will always stick in my mind. A home help (now called home carer) came to get me up, dressed and supported me to

have a wash. When I asked her to pass the bread to me out of a cupboard her response was: "It doesn't say anything about that in your care plan."

Back in 1984 I received about an hour per day home care service. Every Monday the bath nurse came (so no bath on Bank holidays!) and community nurses visited at night. I had no control over my life, no privacy and no social life because the nurse might arrive anytime between 7pm and 11.45pm at night.

You were given no choice about this and it often resulted in me having to entertain friends in my night clothes. On one such occasion the nurse came in to undress me wearing plastic gloves and a pinny. When I asked why she was wearing these, she said "cross infection" to which I retorted: "Funny that, I never knew cerebral palsy was infectious."

In 1989 I was introduced to the Independent Living Fund (ILF) and as a result of this I started to employ my own PA. This taster for getting some control back into my life prompted me to write to the director of social services and ask him if I could swap direct services for cash.

Now, having employed my own PAs for 19 years, using ILF and direct payments has been an interesting experience. Government throws up its arms in horror at the cost of social care for people with high support needs like me. But there are less than 10% of disabled people who receive funding for 24-hour support. Apart from the obvious argument about cost – who would really want to live with six different people anyway?

I employ five PAs, all of whom do one 24-hour shift, and some do two. I also have

one PA on standby for holidays or sickness. Two of my PAs who have left will also help me out in an emergency. I have tried every conceivable shift pattern, but this one works best for me. It is useful to remember that all disabled people are individuals so there will never be one fit to suit all.

## Recruitment and retention

I recruit by placing an advert in an evening paper, which says 'If you want to look after me, this is not the job for you'. I conduct a short telephone interview and then make a shortlist for the interview 'proper'. The reason I do this is because it saves time – if someone tells me they have worked in a residential home for 25 years they are not necessarily what I'm looking for. Institutional attitudes can be very hard to change.

Due to the unique relationship between the employer and his/her employee it is more about "boundaries" than anything else.

One of my favourite questions at the interview is: "I am not looking for friends – why do you think this is?" Some applicants feel they can ask the most intrusive questions, for example: "How many times a week do you take a shower?" To which I respond: "Every other day and twice on Sundays – the same number of times I have sex".

All new employees have a six-month trial which can be extended. As long as my PAs can drive my car safely, support me in my personal care and transfers, I tend to work on people's strengths. If they have IT skills or Cordon Bleu cookery skills, I utilise these. I am fortunate that one of my PAs has management skills so I have been able to make her my scheme manager. (Pg34) ⇨



### Olivia's story

Olivia Frampton is a person with learning disabilities who owns her own house. Though she and her family were commissioning and directing her support service, they chose to commission Choice Support to employ the staff.

They felt this allows them to retain control while avoiding the day-to-day burden of being an employer. Olivia's mother Lynda tells her story:

When our daughter Olivia, who has profound and multiple learning disabilities, was 19 and left her special school, as a family we knew that it was important to put in place long-term reliable care, which would stand her in good stead, hopefully for the rest of her life.

We approached a number of care agencies, and finally commissioned Choice Support to work with us to put together a package of care that would meet Olivia's complex needs, in her own home, around the clock.

The important things to us were, and have remained, the quality and reliability of



staff, the willingness to work together as a team, and the professional abilities that the care team would bring to Olivia to make her life safe, interesting and fulfilling.

Seven years down the line her care team (who I now regard as her extended family) are now all known to me personally, and I look forward to calling in every week or so to see them all. We are fortunate in having low staff turnover, and I very much enjoy being part of the team. Although I live some distance away, they include me in her

annual reviews, medical treatments, care and welfare planning, and activities where possible, and we telephone and email frequently, all of which as a mother gives me great confidence.

Would I recommend self-directed support for someone with profound and multiple disabilities? Yes, I would. For Olivia and for me, it's turned out to be the best of both worlds.



### Joshua's story

Joshua is 19 years old and lives at home with his family. He receives a direct payment which social services pays into his bank account.

Joshua employs PAs to support him with activities on Tuesdays, including swimming, bowling, going to the library, walks, visits and attending a service user committee.

Joshua has enjoyed these activities so much that he has decided to reduce his respite care so that he can spend more time being supported to undertake activities during college holidays.

Choice Support invoices Joshua for staff time and mileage and he pays by cheque. His mother says it's much easier than when they were dealing with social services as Joshua was able to increase his service by an hour each week. Without direct payments the increase would have had to go to the board and be agreed by social services before it happened.

Joshua chooses all his activities on a day-by-day basis so he can do whatever he wants to.

Several of my staff have worked for me for between 10 and 12 years, and it's good to have this sort of continuity.

### Would I go back to direct services?

No, definitely not! I can now get up when I want, go to bed when I want, use the bathroom etc, etc. Having my own funding has enabled me to chair a European disabled people's organisation and travel all over Europe. However, there are stressful times, which, with very little support out there, you have to deal with, often by yourself. Imagine giving someone a disciplinary, then having to get them to do some very personal task for you? There are never any witnesses to what goes on in your home so it's always going to be your word against theirs. Over the years I have been taken to an employment tribunal – and lost. And I've had people who make accusations against you and then deny them. No form of regulation or safeguarding authority will stop this from happening.

### Lack of support

Many disabled people's organisations or user led services have vanished through lack

of adequate funding, even in a climate when the Department of Health has stated that local authorities must work with them. Many disabled people have never been employed themselves, let alone been employers. It was because of this lack of support that two years ago I set up Being the Boss and formed an Association of Disabled Employers to gain a stronger voice.

With the advent of personalisation and individual budgets, what future is there for disabled people to gain their independence? I feel individual budgets will help disabled people with low support needs, but will make little difference to people like myself. Personalisation is the buzz word in social care but where is the money going to come from? Nobody wants to pay for it. Why? Because nobody feels they will need it. Perhaps people should realise that 76% of the total population of disabled people in this country are not born disabled, they acquire impairments during their life. ■

[www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

[www.beingtheboss.co.uk](http://www.beingtheboss.co.uk)

[www.choicesupport.org.uk](http://www.choicesupport.org.uk)

### About the authors



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