

Carolyn's Story:

Carolyn wrote her own story.

A self-directed model changed my life!

Introduction

In recent times I have been asked a lot about how I manage my care support at home. This, together with thinking about the NDIS (National Disability Insurance Scheme) and how support can be much more individualised, spurred me to write about my experiences. I hope it will explain some of what I do and what I have learnt along the way to those of you who might be looking at self-directed supports at home.

Back in 2007 I worked as a research associate on an evaluation of the pilot of the self-management of Attendant Care. That is, a group of people using Attendant Care elected to receive funding directly and organise their care themselves rather than have their funding go through a service provider. During this process I spoke with lots of people similar to myself with high level physical disability using their 35 hours per week for care and support at home. I worked out there are three ways to manage your Attendant Care package:

- A traditional service provider administers your package
- Direct funding or self-management
- A brokerage agency supports you to employ your own staff.

Taking Control

This got me thinking it would be great if I could have more choice, flexibility and control over my own care and make it work better for me. But I definitely didn't want to be concerned about tax, insurance, running a payroll and those types of financial/administrative issues. I wanted the best of both models. I had been doing a lot of the work myself anyway but the provider was taking a large cut from my funding, with little support to me or the care staff.

It wasn't long before I switched from a traditional type of service provider to what's known as a brokerage style arrangement. At the time it was a huge decision but honestly I haven't looked back! I use a financial intermediary or broker to deal with the administration of my Attendant Care package, but I am in the driver's seat – responsible for my own care arrangements. Yes I do the work, but I am in control of my life! I moved from being a client (burden and powerless) to being an employer (empowered and in control).

The Benefits of Self-Directed Supports

Having my own self-directed supports has had many, many benefits for me. My brokerage agency is THE BEST service I have ever had. They are friendly, understanding and helpful, and let you manage the service so it suits you. The board of the community organisation are all people who use Attendant Care so they implement policies that foster good arrangements and ensure participants (rather than clients) are supported with their care, for example, my expenses for organising care (phone, internet and advertising) are covered with a regular allowance.

This has resulted in happy carers who are well-paid and not given lots of paperwork or headaches by any type of “middle-men”. I have gained excellent skills in the process of managing my services - people skills, management, rostering, negotiation and so on. These can all be applied at work and in life. The other great thing about my broker is they only do Attendant Care so they are experts in the management of the funding and can share how others get the most out of their Attendant Care.

Recruitment of Support Staff

One of the things I value most about self-directed support is that I can recruit and choose my own staff (and fire them if necessary!). I can employ someone of the gender and age that suits me, and someone who shares my interests. In my opinion, this is one important aspect of why I have secured a successful team of care staff. I can honestly say after almost 20 years of independent living that I believe the success of my care is based on the quality of the relationships I have with the staff – I have to like the person and they have to like me. They see me at my best and my worst, so I firmly believe that any prohibition on “being friends” is inappropriate and patronising. Many work colleagues socialise together at times.

I advertise through the local paper, university career boards/web pages, word of mouth and sometimes I circulate an email through my wide networks. Facebook and Gumtree are options I have not explored yet but if I was recruiting tomorrow I might try them!

I only accept applications via email as this proves they are able to communicate via email (important as the roster is sent out this way) and allows me to cull people who are not suitable. I then contact people who look suitable by phone or email and arrange interviews. I always interview with a current carer or family member in attendance.

Planning and Day-to-Day Management

I do the rostering, recruitment and management of the carers on a daily basis. My broker takes care of all the boring stuff like insurance, payroll and OHS (occupational

health and safety). They are also very supportive of me in my role. They assist when needed but don't interfere.

I do the day-to-day management of my team of seven carers. What this means in practice is that I do a roster (just a table in a Word Document – I'm sure there are other ways) every six to eight weeks. This is based on each carer's availability and preference to work mornings, dinner time and bedtimes, weekdays and weekends.

It is very empowering to be in control of who is doing what and when – but this does take my time and energy. Coordinators get paid \$60,000+ to do this type of work. There should be recognition that I am managing a team of six to seven staff.

It takes skills in negotiation, and sometimes creative thinking, if shifts need to be swapped or changed in emergencies. Carers contact me directly if they are sick or have a problem getting to their shift. I can then assess the situation and because I generally know the commitments and schedules of each carer it is usually possible to find someone to pick-up the shift. Sometimes I swap a shift, sometimes I offer a bonus if it is very short notice. If I get stuck I have the phone numbers of a few agencies which are contactable 24-hours a day and could find staff. I rarely rely on family to fill-in, unlike the bad old days when I was constantly getting stuck without support, busting for the toilet or missing out on meals.

Before a carer leaves each shift they fill in the hours book and at the end of the fortnight they fill in a timesheet that is checked and signed by me. I then fax these to my broker who arranges the payroll.

Training for Support Staff

I provide on-the-job training to my care staff. I choose what is important to tell them, and I always train them up with one of my experienced carers. I am given five hours of training for each new worker which does not come out of my hours allocation.

My care staff also have to undertake a one day training course in quality personal care, and hopefully soon this can have a neuromuscular focus with the MDNSW (Muscular Dystrophy Association of New South Wales) developing training for care staff. There has been a real gap in training for care staff who work with people with Neuro-Muscular Disability. Often my staff would come back after being trained by Spinal Injury focussed training with concerns about me developing autonomic dysreflexia (a condition common for people with spinal injury not Spinal Muscular Atrophy).

Self-Directed Model Compared to Traditional Service Model

I found that traditional service providers' focus was always on carer issues and OHS, often resulting in them sprouting reasons why they *couldn't* do something. On the

other hand I have found that with self-directed care the focus is on how I can make the system work for me, and I have a vested interest in making it work for the carers – a real teamwork approach.

With self-directed care – I am in the driver's seat – responsible for my own care – yes I do the work, but I am in control. I am able to value my attendants the way I want and in the way I think they will most appreciate. Carers have a greater identity – and we have a Christmas party. Previously I was not invited to my carer's Christmas party. The power dynamic has changed in the relationships; my staff are now actively positive and trying to please their employer, in order to gain more Sunday shifts!

So, as you can see, changing to a self-directed model using a brokerage agency has certainly changed my life!

What Do You Need to Get Started on Self-directed support?

The system needs to provide support for people to get the information they need and develop skills to manage their own services, for example:

- Someone able to stand beside and assist at the outset: To help you build your skills to be able to direct your own support (services often have a different idea about what I need compared to what I believe I need)
- Negotiation/communication skills: These could learnt from generic courses
- System for advertising/training
- Role models
- Information: About your choices
- Access to training
- Scope for backup from agency for emergencies.

I have found great information from an organisation called *In Control Australia*.

<http://www.in-control.org.au/>

What has Assisted Me to Self-Manage my Care at Home?

In considering what has enabled me to successfully manage my care at home, my parents instilled strength in me from a young age to go out and make things happen, take on battles to have your rights upheld/get needs met in a constructive and positive way. I am told my personality is warm, tenacious and determined, I am a “cup half-full” person and big on teamwork. These are things that I believe have been helpful in successfully self-managing my care at home

I have learnt much from my 18 years of experience living independently in the community. I have learnt from my mistakes, from issues in the past and I have learnt what works and what doesn't. I think my own personal resources and skills in managing people are partly related to the fact I am "a people person" and also to my professional training as a social worker. I believe people living with disability need access to this type of skill development.

I also attribute my "in control" style of supports to the type of funding package I have and the brokerage agency I use - which both encourage flexibility, self-reliance and consumer responsibility. Previously it was a constant battle against traditional service providers who operated under the traditional power dynamic of "the professional knows best!" In contrast my own underlying philosophy is that I am an expert in my own needs and have a vested interest in making things work!

My goal is to live the life of my choosing and manage my supports to enable me to do that - and it's happening!

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