

I live alone, and use an electric wheelchair, due to a degenerative muscular condition which is a very slow progression.

I have just bought my own home, and moved interstate, and work part-time in a call centre for social services. I am studying and managing a 'self-directed' individual support package.

When I first started needing assistance of a carer, I was totally overwhelmed by the way the 'system' operates. Thankfully, it was back in the days when we had no waiting lists!!

However, it seemed that because I needed assistance for a shower, and light household duties, the 'system' seemed to think it could take over my life. I had to get used to operating to a schedule of an agency, rather than setting the schedule myself.

As my hours of support increased, I had to advocate greatly, with enormous stress, to encourage the agencies, to understand that the current number of hours weren't enough to enable me to participate in society with 'self-determination' and 'self-actualisation', yet the COST of the current number of hours was more than enough to provide for a support system to ENABLE a self-determined life.

Eventually, I was granted a funding package which enabled me to 'self-manage, direct and employ' my own independent support workers. This was a huge relief, the quality of support workers, and support services increased.

I have gained 'control' of my life, and taken on the responsibility of being a team player, and respecting that my home is also my support workers workplace. The relationships between support staff and myself is a 'natural' relationship.

At times, there is a need for me to use an Agency Provider for support for an interim period of time, which costs a hell of a lot more than engaging my own staff, because agencies are profiteering from my personal needs.

When engaging an agency support worker, I want value for money — I recently paid \$98 for 2.5hrs, yet the support worker received just \$45 for 2.5hrs work.

So while I was wanting to get value for my \$98, the carer was prepared to provide \$45 worth of quality/value work. So when purchasing support workers from agencies, there is a disparity between support worker and customer expectations.

Now, when a support worker has an issue with their employer — this 'energy' is transposed into the client's home, and interferes with the client/worker relationship.

By organising my own services, I gain a quality that cannot be achieved by providers.

My support workers, only work for me. They do not have other clients. They are dedicated to achieving my goals, and we share a reciprocal relationship which is based on respect and nurturing — I care for the well being of my support workers, and they care for mine.

To be able to care and support people to achieve their goals, support workers need to be focused on the client. Support workers need to ensure that they have time away from the demands of caring, to invest their energy in their own 'self care' – ensuring that they move toward their own goals.

The poorest quality of support I have experienced, is when I have used agency provided staff. They aren't focused on my needs, they are tired, they have issues with their Agency Employer, they assume they know it all, and aren't adaptive to change easily.

Plus, there is gossip between workers and providers. If you have a falling out with a support worker, the provider will take the side of the support worker. If you have a falling out with a provider, then this affects your capacity to gain support from another provider. If you report the provider for failing on Disability Service Standards, the investigative body helps the provider to change practices, and all the while the client is left to their own devices to overcome the issues without formal acknowledgement of the wrong doings.

Since managing my own budget, and employing my own staff, I am able to respond to changing circumstances, and emergencies — quickly and easily. Issues are resolved quickly, without a huge 'song and dance'. I can change my plans with short notice, and my support network responds.

I have used my funding to provide for emergency equipment/repairs, and this has been undeniably a major contributor to having a sense of security.

When I moved interstate, the most awkward part was organizing my funding transfer. It was to be expected that when I moved, that I had to give up control of my funding, and let a provider manage my services.

This is absolutely crazy, for a provider could not cover the hours of support that I need with the amount of funding I have, and therefore my whole life was at risk.

Without the support coverage that I had been living with for 12 years, I was surely going to find it very difficult to maintain my income from employment, which then I would not be able to pay my mortgage. I looked the risk of losing everything I had achieved, and did not let the fear of being moved into a nursing home or other type of group housing deter me.

The CSDA states that the client has to be supported by the programs that are offered in the receiving State. Now, this is madness. Just because I was moving to a different location, I was expected to function under a program which took away my ability to determine my support services and subsequently my life!

I had to advocate for myself – and thankfully commonsense prevailed, with a Ministerial decision, however it worries me that my supports are now not recurrent.

The issue of portability of support services is huge. People with disabilities should be able to exercise the human right 'freedom of mobility' — being able to move from State to State, live overseas, move country to city etc., WITHOUT the complicated paper trail, WITHOUT the risk of losing the support structures which enabled the person to be in a position to be able to move from State to State.

The government funding agency is currently taking 3% of my total package to administer my funding. How can a government agency charge me for granting me funding?

If Centrelink started charging customers to pay them their Income Support Payments – there would be outrage.

Frankly speaking, I have found over the past 20yrs of living with a disability, that the system of support services, seems to profiteer from the compassion of support workers, and from the adversity that I am living with. Support workers and people living with disability, are treated very poorly – and the system requires a great deal of negotiation skills and self advocacy.

By managing my own services, I have learnt an amazing array of skills which I am able to utilise within my workplace. Thus, the opportunity to self-manage and self-direct my own support services has increased my employability.

I would like to be jumping with joy, rather than rage, and see a National Disability Support Service, put in place. Where people with disability, are able to go through a training and assessment process, to enable us to employ independent support workers.

Currently, I am doing my diploma in Occupational Health and Safety. This is something that should have been available to me as part of the process for Self-management. When I complete this, I will have other opportunities in my employment, and my home will provide a greater awareness of safety to my support workers.

Self-managed clients should have access to online resources. Online/electronic recruitment packages, and electronic payroll programs, have a place and a National Disability program which adopts Self-management, would generate more business opportunities for:

1. Trainers
2. Suppliers of payroll software
3. Suppliers of recruitment software
4. Suppliers of OHS systems

Self-management engages more people in the 'caring' industry. This occurs because a lot of people have the compassion to support others, yet they either don't have the capacity or don't want to help every Tom, Dick or Harry.

Caring people like to work one-on-one, share connections, experiences and relationships. They take on the responsibility for the well-being of the care receiver, and celebrate the gains, and offer a shoulder for the losses.

If we can tap into this market of carers, (which prefer to be known as 'independent support workers') then we would not have the crisis in staffing that we have been experiencing for the past 10 years.

10 out of 10 for 'independent support workers', they are flexible, and empowered to determine what is right for themselves, so they can support their client.

The staff that I have had that aren't certified carers, have access to short courses to assist them to gain more in-depth skills, and knowledge to help them help me.

There is also development of a tool, which enables a carer to 'tag-on, tag-off', and this enables a software package to conduct payroll electronically and can produce reports for government accountability.

I have team meetings regularly to assist new staff, and to have time with my support workers whereby we can discuss plans, raise issues, resolve problems, educate each other.

There is a role for a case manager, in that they can oversee that the team is working, acquittances. ETC ETC

Please please please – make self-management a National Priority for people living with disability which requires support services.....