

## Living with Individualised Support Services

On Friday, July 23 I participated in the Productivity Commission meeting with Commissioner Patricia Scott convened by Dr. Ron Chalmers (Director General of the Disability Services Commission of Western Australia) . During the discussion several issues were raised with regard to how individualised support services actually operated. As a person with quadriplegia for 45 years I have experienced a range of modes of support service -- ranging from none whatsoever, through to my present individualised support service managed by a non-government organisation. I hope it might be of interest to your research regarding the possibility of a National Disability Insurance Scheme to read a short description of how my individualised service operates.

I have:

- lived briefly in a group home for people with spinal injury,
- lived in the community with only the support of my wife,
- received funding support through a small organisation of 12 people with disabilities where we all assisted with the operation of the organisation,
- received individualised support services through Local Area Coordination, and now by choice
- receive individualised support through a non-government organisation.

The differences between the last two options are not significant. Both work extremely well. In both cases a proportion of my funding was paid to the organisation to support them monitoring my funding and acquitting my funds to the Disability Services Commission. I will discuss the advantages of these systems conjointly as the only real difference for me was that under the arrangement I had with LAC I handled the payment of my support workers myself. I wrote their cheques and was responsible for acquitting the funding to the LAC officer responsible for managing my funding.

Under my present arrangement the non-government organisation handles all of this for me. Each fortnight I simply e-mail the list of support workers and the number of hours and rates that they should be paid. It is not that the previous system was onerous, but I felt responsible for handling public money carefully and always felt that there was the possibility that some expenditure could be called into question, or that the money in the account, or the rates of taxation paid might not be regarded as accurate. This never happened over more than a decade of receiving support through LAC, but when I heard about the way the non-government organisation operated it seemed to provide an extra line of protection.

In addition, the non-government organisation (My Place Foundation) provided me with any level of support that I chose from everything being done for me (which did not want) through to the present system whereby they:

- supply me with information packs for prospective support workers,
- pay support workers directly into their bank accounts according to the hours I have e-mailed for each,
- calculate taxation, superannuation and anything else with regard to each support worker, and
- maintain all records for support workers such as Police Clearances, tax and super paid,
- send me a regular information about the amount of funding spent in comparison with projected expenditure levels.

The information pack mentioned above contains draft duty statements, employment contracts, suggestions for support worker's behaviour, pro formas for medical certificates, superannuation fund selection and a taxation notice for the ATO. Many of these are also supplied in electronic form so that I can adjust them to suit the needs of my particular situation.

There is a Coordinator assigned to me who I can contact if I have any questions or need any assistance. I feel free to contact the Coordinator if I have any questions about the appropriate use of any of my funding, or if I need any help with recruiting additional support workers. The Coordinator will come to have a cup of coffee with me periodically if we have had no other reason for face-to-face contact. This is part friendliness and part a check to ensure that everything is working as it should be.

I have chosen that I will recruit, train and manage my own support workers, however I have found that it is extremely helpful to the support workers themselves if they can join in the training programs operated

periodically by the organisation. A support worker who had been with me for more than 4 years before she joined in the training, and who is quite outstanding in her role, surprised me by telling me that she wished she had been able to undertake this training before she started as a support worker! It did not occur to me to do this at the time because I was not then under the aegis of the non-government organisation and did not know about such programs.

Typically I obtain support workers by placing 'help wanted' notices at the local shopping centre and university. Occasionally I have placed a notice with the Commonwealth Government job vacancy website. I have also been extremely fortunate with the support workers who have helped me over the last 20 years. The original support worker that I began with back then still works with me! Several have worked in excess of four years.

I was also very fortunate to have a Japanese nursing sister work with me approximately 8 years ago. There were some language issues as her English was fairly limited but these were all worked through - at times with hilarious misunderstandings -- none of which had any unfortunate results. When she needed to leave to work in her husband's restaurant she arranged her own replacement (of course with my approval) and she trained her replacement in Japanese. This began a chain of Japanese support workers as many Japanese nurses were studying at the university nearby to complete their English qualifications so as to begin nursing in Australia. They were usually able to work for about six months and each one would find a replacement when the time came. This is just happened again as recently as this month. I have had the good fortune of meeting a whole chain of lovely people. They have all taken their role extremely seriously. They are punctual, reliable, polite, careful and interesting people in their own right. My wife and I have been able to reciprocate by assisting them with learning English, preparing essays and speeches and understanding Australia's quaint habits.

Not all of my support workers have had any nursing training, or in fact any relevant training at all. I provide all of the necessary training. At the moment I have five support staff. My original helper who is English could claim only that she had assisted her mother who used a wheelchair as a result of an accident. The fact that she has been with me for more than 20 years speaks for itself.

The next longest serving support worker (more than four years) has an accountant's degree from Japan, but did not want to retrain for accountancy in Australia. She wanted to become a support worker. The next longest (just over four years) is a Chinese lady from Malaysia. She had no experience at all as a support worker. When I asked her about her experience, she said that she was a mother and asked what more there could be to know them that? She is especially helpful as she has a little bit more time flexibility than the others and often can fill in if one of the others needs to go somewhere else. She also speaks Indonesian and as I am trying to learn this language, she can help me to practise.

Over the years I have had support workers from many countries including Iran, both male and female support workers including at least one who was gay, a couple who looked like bikies and several with actual training as support workers. My preference is to get people who have not had this training with other people as there is often a lot of unlearning needed to make it work for me. Once they have started working with me I am very happy for them to have the training provided by My Place Foundation. I have never had occasion to sack a support worker!

Over more than 20 years I have only twice needed to seek emergency assistance from an agency that provides support workers on call. Of course these are expensive, but if you need help at a particular time they are very much to be appreciated. Both of these occasions were when I experienced problems associated with quadriplegia outside the times when my support workers were present. Had I been able to contact one of my support workers, and had they been free, I am confident they would have come to help. On other occasions when I needed help I was able to contact one of them and they came quickly.

When one of them needs a vacation we discuss whether one of my existing support workers is able to fill in for them, or whether we need a temporary replacement. Over recent years it has been fairly easy to get a Japanese support worker for these vacancies. On one occasion however when I asked a My Place Coordinator if she knew any person who could fill in for a fortnight, she asked her son who was studying at university. He had had no experience, but was easily trained as he was intelligent and willing. I had the joy of helping him refine the final draft of his honours thesis and received an acknowledgement in the frontispiece.

I mention these irrelevancies to indicate how I have benefited from a range of support workers. In addition to their actual support I have enjoyed getting to know them and in some cases learning more about their country of origin and social customs. I regularly receive e-mails from support workers I have not seen for more than a decade. They have become friends. I am well aware of the necessity to maintain a suitable working relationship, but when they have to leave both my wife and I feel that we are losing contact with a friend.

I use my support time almost exclusively for direct personal care -- helping me with showering, dressing etc. I would like more opportunity to get help with other aspects of my life such as gardening and photography. I am aware that my funding can be used to pay a support worker to accompany me if I want to try to photograph a landscape for example at sunset, and if I wished to try propagating some fuchsias (which is another deep interest), however I have never felt really comfortable with using my funding for this purpose, nor have there been many spare hours of funding. This is not in any way a complaint! I am extremely glad to have the funding. It has enabled my family members to be family members rather than being asked for some assistance whenever they appear.

The present system works extremely well for me -- as did working with LAC. Both contrast starkly with my experiences staying in a group home or as a member of an organisation of 12 people with disabilities who shared the responsibility of managing an operating the organisation.

In the group home everything was provided and decided for you. Mealtimes, menus, the staff assisting you, the décor, when you woke up, when you went to bed and even who visited you, were decided by the management. If that is the lifestyle that you wanted then it was perfect! However it is very different from a 'normal' way of living. It was also far more costly than living in the community with support.

After living in the community with the support of just my wife I was fortunate to be included in a Commonwealth initiative to encourage people with disabilities to live in the community. I received a small amount of funding as part of the small group of people with disabilities mentioned above. We were very grateful for the funding but the experience was nothing less than a nightmare. I am aware that there are several organisations of this structure that have worked quite well for many years. In our case there were two extremely dominant individuals who systematically made life distressing for all of the other members. It got to the stage where no one in our house would answer the phone in case it was one of these two people.

All of the members of the organisation desperately needed the funding to arrange their support services, yet several discussed leaving the group. It got to the stage where the rest of the group contacted the Disability Services Commission to express our deep distress at the present arrangements and our wish to split the group into two. After some discussion, members were offered the option of staying in the organisation or transferring their funding to LAC. All of the members decided to transfer to LAC. There was an incredible level of bitterness from the two people who caused the distress, yet after 12 months all members, including the two who had caused the problems, expressed the belief that working with LAC was a much better system!

This experience is not intended to suggest that organisations of people with disabilities collectively managing their own arrangements cannot work. If those two members had not been part of the group it would have worked well. However it would still have had issues relating to workload and accountability that simply don't apply if your funding is managed by LAC or a suitable non-government organisation.

If any of the above comments leave questions in your mind I would be extremely happy to provide additional information. I was motivated to make the submission because I believe that my present arrangements for managing my funding are the best I could imagine.

Yours faithfully

Dr Philip Deschamp