

I have had a disability for 15 years, which means I have been receiving some hours of help from the personal support category of the government social services.

Prior to this I was a successful business person and so I have watched how the system works with the eye of a businessperson and often been struck by how ineffectual and inefficient the system has been and how unrelated what happens often has been to my actual special needs and any sensible desired outcomes that a provider might want, *particularly independence and productivity*.

At first I received this assistance via the standard system of being assessed by a NASC and then simply given an agency. This was of some help, and definitely better than having nothing, as I need someone to talk to focus and be able to make things happen. But the person had typically received no brief at all as to the nature of my disability. One told me she was not allowed to see my assessment and assessed needs, which seemed ridiculous. Generally, I saw many things that would have appalled the actual policy makers I am sure. The focus seemed very much on the needs of the agency, there was an inhumanity to clients and there was neglect, for example people not turning up to the home of someone with alzheimers or other brain impairment, and yet no phone call etc. I believe the very low pay and no questions asked attitude to employing these helpers, means that although some are very good, many are ill-suited to such roles, and can have problems of their own that they talk about, and the people being helped feel obliged to try and help them. There may be a low level of understanding of the ethics that should apply in these situations, for example that it is inappropriate to be constantly talking about one's own problems, have a good look through someone's possessions when they are believed to be asleep, when this is unrelated to the job, or help yourself to ice cream from the fridge. When a helper is found who does understand these things and has the right skills, it is a very different experience and enormously helpful.

Approximately seven years ago I heard about a pilot scheme to provide individualised funding to people with complex needs, and I grabbed this with both hands. This meant I could advertise for a helper with appropriate experience or qualifications.

I was assessed as eligible and I certainly had some learning experiences, I have had to relearn things I knew perfectly well when I was well. However I am grateful for these, as I have gradually got better at it and more confident. The individualised funding means a coach comes at the beginning and telephones you or can be contacted and this is good. It has been a much better situation for me. But still the kind of people who apply for these jobs, are very focused on doing housework and I have to repeat over and over again (when I am able) that I want them to help me get started, or do tasks WITH me, because it is more helpful, and will achieve more in the long run, even if it seems slower to them. So, the individualised funding was definitely better than the old system.

HOWEVER, it will only be if the enhanced funding scheme which is currently being piloted in Tauranga, I understand, is rolled out to include the rest of the country, that I will finally be able to access services and be actually productive. I will be able to hire the services that will actually help me to do so. They might actually cost more per hour and not fit with the current rigid system, but my experience so far has shown me it will COST LESS IN TOTAL. It will be the RIGHT HELP. and after many years I believe I would **finally be able to achieve something productive and give back to the community.**

Re the agencies that provide support services for people in our situation. I found Manawanui, who had been set up specifically to carry out individualised funding in the pilot has generally been excellent. I was very dubious though when I heard individualised funding had later been rolled out through existing agencies. I believed this was pragmatic only and likely to perpetuate existing deficiencies in those agencies that are very poor. To give an example, the agency I was first assigned to, did not visit and check how I was doing until all those articles in the paper about someone being treated badly in a rest home. It seemed to take a bad event like this to start to make more of an effort. Surely these sort of people should not be there. Or processes should be such they know they can't get away with it.

One service I access is that I use Manawanui to administer my 'payroll.' As someone who had previously been in business I saw weaknesses at the beginning in the financial side, including the reporting, but this was much improved after the arrival of the current CEO Marsha Marshall. **I had previously wondered if it was the background of providing people with more experience in government than real world financial administration, that was causing the issues. It seems to me that as you are reporting on effectiveness this side of things could well be an issue. And the ability to communicate to clients, particularly disabled clients, about the financial matters that affect them – communicating very simply and step by step what their responsibilities are and who does what and so on, is very important to us. WE need summaries and the essence of things, and checklists, not to be drowned in copies of laws and contracts and expected to work these things out for ourselves.**

While I'm doing this, I want to say that for many years the pieces of paper from government agencies contained a lot of jargon words (like NASC) and I had no idea what they meant and didn't know how to work it out. When you are very sick and blurred, unless things are very simple and obvious, you are lost. There must be many people like this.

It is hard to understand that there might be things to help you, that you can complain. This took me years despite an intelligent background. When finally the relevant part of a document came into focus, all it said was that I should ring (name of organisation) to complain. I guess they do not want to put a personal name in case that person leaves, but believe me these abstract concepts and incomprehensible jargon does not work for us.

Whatever paper is provided there should be in very large letters, perhaps something to put by the phone, of the person who could help us. And then 'if not available, call (agency) and mention that you would like to talk to x kind of person.

As your draft report seems to suggest you realise, the bureaucracy and the jargon words and letters, and the various different agencies, District health Board or Government etc etc, are quite foreign and incomprehensible to us when we are not well and only have a small amount of concentration or effort. We often can't differentiate between them. Please keep it simple and give us a simple lifeline we can access. If I had had this and been quite clear about it, it would have prevented a lot of suffering, or dealing with 'help' that sometimes made things worse.

"WRITTEN WITH ASSISTANCE"

