

My name is Liz, I am 25 years old and I have Cerebral Palsy. I completed a Bachelor of Social Work in 2007 and a Certificate 1V in Training & Assessment in 2009 and currently work at Annecto – the people network.

My personal support at present consists of:

1. 25 hours per week under my Individualised Support Package (ISP)
2. 9 hours per week of assistance under the Work Based Personal Assistance Scheme via Department of Education, Employment and Workplace Relations
3. A small package of funding under flexible respite per annum

These supports assist me to have some independence in my life but it does not give me enough flexibility to live independently and I am continually socially isolated.

There are certainly some issues that I deal with on an ongoing basis:

1. Reliability of attendant support workers – I have issues with workers who either do not arrive or arrive late. This is very disruptive for myself when I am heading to work, an appointment etc and also for our household. Without a support person, I am unable to do basic tasks such as getting in and out of bed, showering & dressing, going to the bathroom, getting the train, eating.
2. I also have an issue with the training and with the professionalism of some support workers. The fact that support work is viewed as a 'stepping stone' to other things is an issue, people are in it for a short time which gives no continuity of support.
3. Family emergencies are a huge issue for me and something that I think of often. There needs to be easy and quick access to be able to get extra funding when needed to assist me during a family emergency.
4. The system as it stands is difficult to navigate even when you know exactly what you are entitled to. Also, there is a lack of continuity with getting the supports you need.
The requirements/assessments/eligibility are totally different for every system ie: pre school, primary school, secondary school, TAFE, university and employment. I have been involved in each of these systems and have often

become frustrated the varying requirements for each. Particularly given that my disability and my requirement for support has not changed.

Currently I rely predominantly my mother, to provide the majority of my support. It is my major concern that if/when something happens to my mother, what happens to me? Do I vegetate in a respite house waiting, waiting, waiting for permanent accommodation that will suit my needs?

My priority is to live independently out of my family home but this is not a possibility in the near future. Quite apart from the lack of suitable accommodation I do not have enough support hours to live independently. I would also love to travel as other young adults are able to do but I am also limited financially by the lack of physical assistance.

Equipment should be fully funded not just partly funded. In order to have the most suitable wheelchair either myself or my family need to be in a position to contribute several thousand dollars. Or to replace my ceiling hoist which is beyond repair a balance of \$1500 is required. Given the limitations of employment in conjunction with the receipt of a disability pension expenses such as these which occur on an ongoing basis are continually difficult to deal with.

The Long Term Disability Care and Support Scheme needs to provide a more reflective and accurate picture of supporting people's lives. At present the funding models are fragmented and inequitable and are not realistic in providing or promoting independence for people with a disability. Currently there is excessive pressure put on families and on the general community to remove pressure from the formal disability sector but this is creating even greater pressure on families and on these informal supports.