Background

My husband and I are full-time carers for our 21 year-old middle child. Our son has a severe intellectual disability along with severe cerebral palsy. This combination has left him unable to communicate, immobile and lacking much co-ordination. He also has a digestive disorder which gives him a lot of pain and, coupled with his inability to tell us about it, much frustration. Naturally this has led to behavioural problems such as screaming, biting himself, and hitting us.

Inequality of Funding

Having recently moved from NSW to QLD, I can’t help but notice the discrepancies in disability services across the states. This leads to a huge imbalance in funding which is most unfair.

An example of this is post-schools funding. Our son had, in NSW, a package that gave him 21 hours/week, including a paid position of 6 hours/week in a sheltered workshop. Imagine our horror when his QLD package was given: 3 hours/week.

Even across QLD, no, across his town (Toowoomba) this is a very unfair package and apparently it depends on the money available in the year you apply. So, some people with quite mild disabilities are currently on 15 hours/week and their carers feel as much guilt as we feel sorrow.

*I strongly suggest that only a National funding body could change this.

Funding For Life

Our son was diagnosed at 5 months of age. However, even after 21 years notice, the Government is still unable to provide him with a home for when we can no longer manage.

It has always been clear that our son will need care beyond our lifetime and it would make a huge difference to us and him if this place had been reserved for him, all that time ago. Not only would it relieve worry for us and his siblings, but if that place could also have been used as respite, it would make his eventual transition far easier for him, us, and the care facility.

As our son’s condition is not expected to improve, it seems pointless to repeatedly ‘prove’ his need for assistance.

When we came to QLD, we needed to re-apply for continence products. This entailed a) keeping an input/output diary- we had to measure his fluid intake and then weigh his nappy 2 hourly. This was hugely expensive. And b) send a urine sample for testing- This was not only pointless but ridiculously difficult as adult male collection bags aren’t made. This meant we needed to use a ‘baggie’ and masking tape, resulting in a huge loss of dignity and pain. All this to ‘prove’ that he needed nappies!

Now that Medicare is taking over the Commonwealth continence subsidy scheme, we have had to ‘prove’ that we are his carers!

*A central agency that collects, stores and gives information is needed to save the expense, time and emotional upheaval of repeating ourselves.

Groups Who Need Additional Funding

From our experience, those who have no communication are at great risk of injury, abuse and fear.

Our son was offered 15 days/year in a beautiful, brand new, purpose built respite home. We couldn’t believe our luck! Until he came home after his first full-house visit with gouges on his chest and arm which occurred when he was left unsupervised with other clients.

As our son can’t talk, he has been unable to tell us who attacked him and so we are never sure who he would be happy to sit with, etc, when in groups.

*People who rely on others for their communication really need to have one-on-one care at all times to reduce their risks and enable them to live fuller lives.

Power of Decision-making

Surely those whose lives are most affected, ie, those with disabilities, their families and/or carers, should be given the power to make decisions.

But those decisions can only be made effectively when enough information is provided.

Currently, the system is so fragmented that it is extremely difficult to find your way through it.

Both funding and information are distributed in a way that makes them really hard to access.

*A single, national body that provides both information and funding needs to be established to streamline services and cut costs of delivery.

Thank you for the opportunity to add my voice.