Submission to Productivity Commission Inquiry into Disability Care and Support.

First, thank you on the sensitive, thoughtful, respectful and constructive work you have done in exploring the issues related to the support and care of people with disabilities, documenting your findings and presenting such positive and exciting ways of improving our community. I found myself filled with new hope and optimism about the future as I read the report.

When consideration is given to adopting a scheme such as the proposed National Disability Insurance Scheme, attention must also be focused on the cost of doing nothing. The current system has many obvious and hidden costs and I would like to see more emphasis in the final report put on the enormous financial, emotional, health and social capital costs of the system we currently have. As an example, I would like to relate a time in the life of our family that highlights some of these costs.

Background:

*Note: *I have changed my son's name to protect his privacy.*

My 25 year old son, Ben*, has a wonderful wicked slapstick sense of humour; an impulsive, can't-wait energy; and a full-on joyful engagement with life. He also has cerebral palsy, an intellectual disability and epilepsy. He has a sister, now aged 22, with whom he has a close and loving relationship and who has, in part because of her experiences with Ben*, become a health professional.

Until 2 years ago he lived full time with us. We have a close family, and my husband, daughter, mother and brother have been great supports. Over the years we tried various respite options but none worked well. In home respite was characterised by a rapidly changing cast of workers, each of whom had to be introduced to Ben* and taught about his communication, epilepsy and appropriate activities to do with him. The quality of these workers was poor, with few exceptions. They were unreliable in terms of time, and sometimes they did not turn up at all. On the whole they did not engage well with Ben* and I felt uncomfortable leaving him with them, as he was bored and, when his epilepsy was more problematic, unsafe. On one occasion I came home to find Ben* in front of the TV with nothing to eat or drink, and the carer sitting at the kitchen table with all my books about parenting spread out in front of him. He had recently become a stepfather and was using the time to read up on his new role!

Interchange was an exception. The youth group activities were greatly enjoyed by Ben* and the 4-5 hours on a Saturday every month or so gave me a chance to do things with my husband and daughter. But it wasn't enough.

A time of transition

As Ben* reached his late teens/early 20s he became increasingly unhappy with having me assist him with his personal care – washing him, shaving him, cleaning his teeth, dressing/undressing, cutting his nails, washing his hair, wiping his bottom etc. I could understand his perspective – he wanted more independence, wanted not to be dependent on his mum for all these tasks – but the problem was he couldn’t do them himself. He became increasingly angry with me – lashing out, throwing things at me. Not all the time, but suddenly, when he was filled with rage about his dependence. At times he took it out on his younger sister too, and even sometimes his grandmother. He could be dangerous in his anger towards us at those times.

At the same time, for a variety of reasons (retirement, ill health, busy lives) my informal supports were dropping away and I could see we needed help. I reluctantly put him on the ‘list’ for accommodation. I knew accommodation was scarce, and that we would have to wait. For the next few years we struggled on as best we could.

Then, in 2009, he was offered ‘a place’ in a supported accommodation house. We looked at it together as a family, decided that it was, on the whole, suitable and went through the process of transition. Throughout this time I was filled with agonising sadness and guilt at the thought of ‘giving him up’, or ‘putting’ him in supported accommodation. I had real feelings of having rejected and abandoned my son, even though my logical self knew it was the right thing to do.

The first year was terrible. Ben* can’t speak and uses a variety of visual cues, vocalisations, gestures and signs to communicate. If he can’t make himself understood he becomes frustrated and angry or, more tragically, sad and withdrawn. I did all I could to support the transition: I bought furniture that echoed his own at home; fabric boards for his room and the ‘family’ room to which staff could attach photos with velcro for Ben* and the other residents; I bought a computer so Ben* could play games and listen to music as he did at home. I also bought a laptop, colour printer and laminator so staff could make communication sheets of activities done with Ben* and the other residents – the mainstay of Ben*’s day to day communication.

But so much was working against us. Staff turnover was high; in that first year there were 4 house supervisors and many months between with no house supervisor at all. The staff were demoralised and without leadership and there were many communication breakdowns. They felt too overwhelmed by the day to day tasks to learn new ways of seeing their role and developing new skills (including learning about Ben*’s communication and philosophy and strategies that underpin person centred active support). Ben* was a disruptive influence in a previously very quiet non-demanding house and some staff were judgemental and punitive. When Ben* refused to eat at the table with the others, one staff member said they were going to put him on Sustagen. I flatly refused my consent for this, explained the importance of understanding the effect of his distress on his appetite and when I threatened to use the complaints process, she backed down. When Ben* was disruptive after he had been home for the weekend another staff member told me to leave him there and not take him home for 3 months. Again I flatly refused. As staff left, more casual staff were used. Once, when I rang up to see how Ben* was, the staff member who answered the phone called to another *“It’s Ben*s mother on the phone – she wants to know how he is - which one is Ben*?”* The house had 4 other residents, all in their late forties and fifties. They tended to be more isolated, passive and sedentary people than Ben* and he found it hard to form relationships with them.

Ben* became increasingly unhappy and agitated at the house. Then he began to refuse to get on the bus to go home from his day program in the afternoon. When staff tried to encourage him to get on he lashed out at them. For a time it was taking up to 2 hours to get him on the bus in the afternoon. He was stressed, and posed a danger to himself and others at these times. On one occasion he injured a staff member who is still, as far as I know, on Workcover. This went on for months – many strategies were tried and none seemed to work. Both Ben* and I were extremely distressed. My own work suffered and I considered resigning because so much of my focus, my life energy, was going to Ben* and I felt I simply did not have the ability to work as well. I considered taking Ben* home again, and it was only my daughter's support and advocacy that enabled me to continue insisting on the changes I knew were needed in his environment in order for him to enjoy his life in his new home. The two I focused most on were the staff learning to communicate with him more effectively, and for him to have something to look forward to in his life. It didn't seem too much to ask.

Ben* has always derived great joy from the anticipation of an upcoming event – it can be a movie, play, concert, Christmas, Easter, birthday or other event that is exciting for him. To do this he needs photos that enable him to talk to others about what he is anticipating and for those around him to share his excitement.

About a year ago things started to improve. A new operations manager was appointed and was a strong leader, supporting the staff to implement policy – including Person Centred Active Support. A key worker was nominated for Ben* and he started to put in place some of the strategies outlined in Ben*'s Person Centred Plan. They now regularly look in the paper and on YouTube for upcoming events and plan together what they will go to, and then make photos about it so Ben* can share his excitement with his family and those at his day service.

Throughout these last 2 years Ben* has come home to us every weekend. I have felt he needed this time as an island of love at a time of tremendous change – a place he was listened to and understood and comforted by familiar routines.

He is now much happier. He has the independence from me he so craved and is no longer angry and assaultive towards my daughter and I. The current house supervisor has been in the house for nearly a year, the staffing group is much more stable and Ben* has a very good relationship with all of the key staff. He has formed a touching nurturing relationship with one of the other residents in the house. He has much to look forward to: forthcoming movies (Pirates of the Caribbean, Harry Potter and Tornado Ally), the Tutankhamun exhibition at the Museum, and the Phantom of the Opera sequel: Love Never Dies. Some of these he will go to with members of his family and some with staff from the house. He has had no behaviours of concern for many months. It's wonderful to see that once again we are able to share with him his passionate, excitement when looking forward to upcoming events and that he, once again, has so much joy and fun in his life.

The facets of this story I particularly want to highlight are:

- The **natural desire for independence**. Many young people, no matter the severity of the disability, wish to move away from dependence on family to a more independent (of family) life.
- The **tremendous stress that can be placed on families** when a young person – particularly a strong young man – expresses his anger and frustration in destructive and assaultive behaviours.
- The agonising **grief and guilt that are currently so frequently experienced by parents** putting their son or daughter on the Disability Supports Register or equivalent for accommodation when they are no longer able to cope. I would hope to see in the future

  - That young people are offered opportunities to leave the family home at a developmentally appropriate time – say between 25 and 35. If this was seen as a natural, expected transition grief, guilt and feelings of abandonment and rejection would not dominate; rather it would be seen as a rite of passage as it is for peers and siblings.
  - Such a plan would facilitate young people moving in together – a situation far more likely to lead to friendships and shared interests than the current situation where young people usually move in with much older residents when a place becomes vacant because of death or admission to nursing home.

- **The costs of the current system**. For us this meant:
  - Physical and mental **health**. When Ben* was living at home my daughter and I incurred many physical injuries and were frequently stressed and unhappy.
  - Both day support staff and house staff were **stressed** to see Ben* so upset, particularly those who had known him before his move out of home. This was made even worse by having to cope with my anxiety, sadness and stress!
  - Additional staff **time** – required both at the day service and the house – to support Ben* during the many months of challenging behaviours. Including up to 2 additional hours every weekday when he refused to get on the bus to go home and would run up and down the road, lashing out at anyone who came close.
  - A great deal of the *time* of house staff, day support staff and disability service managers was consumed in many many meetings with each other and with me about how to try to address my concerns and Ben*s distress. I was preparing my case to put before the Disability Services Commissioner when things started to improve so I did not go down that path but could easily have done so if the personnel and timing were different.
  - **Staff injuries** sustained during his assaultive behaviours, including an ongoing Workcover claim.
  - **Property damage** sustained during his destructive behaviours
  - **Mental health**: Both Ben* and I were stressed and unhappy. I developed a severe anxiety disorder requiring medication.
  - **Erosion of my own ability to work**. I came so very close to resigning (and the community would have lost my taxes and had to pay more in welfare payments)
  - As well, of course, as the tremendous **stress** and **suffering** both Ben* and his family experienced.

In conclusion

I urge the Commissioners to highlight the personal, health, financial and productivity costs of doing nothing. The current system of supports for people with disabilities and their families is inadequate and leads to enormous suffering and loss of potential contribution. People with disabilities and their families have so much to contribute; we want the opportunity to do so.

**Not his real name.*