Dear Commissioners,

I am presenting my views and suggestions for consideration by you, in response to the Australian Productivity Commission's Inquiry into Disability Care and Support. I represent a group of carers across Australia, whose children's lives are assisted by technology. In particular, families of children who are dependent on Tracheostomies, Ventilators and G-Tubes.

These children depend on us as their parents, to deliver around the clock care. We are a minority group within a minority group and many of us, due to the ongoing stresses and overwhelming demands of our caring roles, have become isolated. We face the same systemic issues concerning the provision of services and respite care that most carers face. The majority of us are too tired, busy or unavailable to attend community forums, make submissions to inquiries or advocate for ours and our children's needs and are therefore overlooked.

We are responsible for every breath our children take. We deliver a level of care to our children that doctors and nurses train for years at university to learn. We know how to save our child's life and we are always 'switched on' to do so. We live like this because the alternative, which is leaving our children in hospital, is unthinkable. There are those of us who don't have a choice though. Those who do make it home, do so knowing that there will be regular trips to emergency, and many more hospital admissions. We attend regular follow-up clinics, specialist appointments and therapy sessions. Some of us have to travel for surgery or specialised care. If you've ever tried navigating your way through airport security with a pair of scissors - necessary to save your child's life in an emergency, a car seat, mobility stroller, an oxygen cylinder, heart rate monitor and suction unit, you will understand the difficulties this necessity for travel presents.

We give up our jobs, our superannuation, and our freedom and we trade it in for an overwhelming amount of responsibility that comes with little support and even less sleep. We don't complain. Partly because we don't have time, partly because we don't have the energy. Mostly, because many of us have come so close to losing our child, that we are grateful for this alternative. We embrace our children's medical needs and learn to care for them. We navigate our way through the health care system and then after many weeks and sometimes months, we make the triumphant transition from hospital to home. Relieved to have made it through all this in one piece, we then find that we need to learn to navigate our way through red tape and bureaucratic processes to access adequate support within the community. That is for those of us who are fortunate enough to have access to community services.

The responsibility of caring for our children is too difficult for many respite agencies. They face funding, training, OH&S and liability issues, so our needs are often left unmet. To combat this, we co-sleep with our children to make sure they wake up breathing, accompany them to school or home school them, to make sure they get an education. For those of us fortunate enough to have family around us, we train them, at least the ones who are willing/able to take on the responsibility. Some of us will even train staff from agencies, teaching them the intricacies and importance of tracheostomy care, or administering and caring for a G-tube ourselves. What choice do we have? In the Australian Capital Territory families receive up to 7 nights overnight care but struggle to receive flexible daytime support. For those in Western Australia and Victoria the level of support is individually funded through the CATCH and HACC programs and although it is far more flexible, these programs still have their flaws. New South Wales and Queensland families, receive no respite or support at all.

I would like to see the development of an Australian based online forum, information hub and support group for families and individuals caring for a child who is dependent on technology. I would like to see this modelled on the www.tracheostomy.com website, based in the USA, with information and links to support for Australians. We all have similar needs and experiences, so providing us with an online forum would allow us to come together to support one another. Furthermore, it would provide us with a voice, so we can outline our needs and work together with the Australian Government to find solutions to the difficulties this amazing group of carers face.

There is currently a group of parents based at the Royal Children's Hospital in Melbourne, who have formed a small support group with an online presence. The On Trach website is moderated by RCH staff and parents, however the website (http://mc2.vicnet.net.au/home/ontrach/index.html) is difficult to navigate and hard to find. Despite this, it has still been effective in assisting some families to receive the information and support they have needed to advocate for their child's needs. The benefits of this type of support network are far reaching and would provide families with the much needed information and support that community services are currently unable to provide to this courageous group of carers. I believe that the best model, is one that is funded by Government and developed and moderated by the major Australian hospitals, in conjunction with the above mentioned families.

Thank you for your time and consideration. I urge you to visit our website/blog www.keepingtrach.com, to develop a better understanding of some of the challenges that families like ours face.

Kind regards,

Melinda McFadden