Personal Response to Productivity Commission Issues Paper.
Apologies for format, or lack of, always a time shortage .

All people with a disability should be included as all will need help ,albeit to varying degrees.

The severely and multiply disabled are a disadvantaged group along with the autistic, probably because of the large input of dollars needed

Parents need options/choices in looking at therapies/therapists for their children. We rarely know what our options are in the present system and no one is telling. Often parents are made to feel guilty for the cost of services they require. There are so many advances in equipment, communication devices, splinting etc yet many of the therapists will not prescribe if they deem it too expensive, even though the cheaper option often breaks, is unsuitable and of little value to the client. My child has been fortunate to be involved in a program based on the Principles of Conductive Education which has helped to keep her fit and healthy and learn many things. However I found a lot of resistance along the way from many in the medical profession and disability organisations , those who were supportive could not do so openly because their superiors were against it.

Trying to maintain this level of exercise for my now young adult is extremely difficult, reaching 18 seems to mean an end to needing services as they diminish rapidly. No one seems to think further learning is necessary, indeed I wonder where all the severely disabled adults are. Many of our children develop more problems as they grow and age and often this could be lessened or avoided if more preventative measures and timely replacement of equipment were available.

In S.A. we had an excellent State wide Complex Communication Needs Project .Hooray , at last some real help for adults from passionate and highly skilled and informed therapists. A very large boo to our govt for not re-funding it. Is there a deliberate policy to make sure the nonverbal remain so? The lack of concern by some to provide a voice for the voiceless is infuriating. Communication devices are expensive, acknowledge this and fund them, giving someone a voice is a gift greater than we can imagine.

The support an individual needs must be flexible and open to change, No one can predict this , and the disabled should not have to go through lengthy assessments .often by someone who knows nothing about them and is restricted by the budget of their department. Waiting for assessments is itself an insult, if I need assistance in my life I deal with it as needed, the disabled wait and wait and wait and go on waiting. Some years less funding may be needed than others but it should always be available if needed.

Existing assessment procedures leave me feeling dismayed, as does the lack of hand over on reaching 18 and the lack of regard for parent/carer knowledge of the clients abilities.

Families are no longer content with all services offered. Information from around the world shows that often we are not being given the best services /equipment for our children and that valuable work being done overseas is often not being recognised here. To be able to choose therapies /therapists as we do in our own lives would sometimes provide a better option.

Houses are almost always a problem, expensive to change ,easier if all new housing followed simple rules for accessibility.

Going to a doctor ,dentist, chiropractor or anywhere it is necessary to get out of a wheelchair is impossible for many disabled adults.We could not access the x-ray dept of a hospital recently because they would not release the x-rays so our private physio could view them. Finding somewhere else with a lifter was challenging, Perhaps one day medical centres might accommodate all members of society, Staying in hospitals with our children is in many cases imperative , in my case usually appreciated by staff but in others not so. Nonverbal people do need someone who understands them with them in these situations.

I sincerely hope that a workable system can be put in place so that we as parents can spend more quality time with those we love instead of constantly having to spend time fighting for their rights, and they can then work towards achieving their potential.

Many families need in home care, some prefer the opposite, some both. We all need to have an emergency service for when we are ill or hospitalised, some arrangement that can be put in place immediately, night or day. A universal documentation system covering all our child;s needs which we could update and which could go with our child would be an asset .

I recognise managing such a system would be difficult but the present system does not work. Less expensive items such as incontinence aids, repairs to equipment, therapist visits, new switches, new wheelchair chargers ,splinting[not always covered but yet again often vital eg second skin splints and suits] often need to be purchased quickly. Peoples needs can change at any time, the existing waiting times for assessment and eventually approval are ridiculous. No one as an ordinary consumer would tolerate this.   In many instances a prescription from a therapist should be all that is needed, Items such as wheelchairs, communication devices ‘toilet/shower chairs all have a limited life but are a vital part of life to the disabled.

Ongoing support and training for clients, families and carers is vital, especially in areas such as communication, I regularly aquire new knowledge and my child should also have that right. Updating communication systems is an ongoing need and access to therapists experienced in AAC and who have the client’s needs at heart is imperative.