Submission to The Productivity Commission for Disability Care and Support

As a parent and a 24 hour carer of a young adult, the time I require to do justice to responding to the Disability Care and Support Productivity Commission Issues Paper is not available but I wish to contribute with our experiences of the current system, the waste that we see and the services we do not receive.

My daughter (23) was one of identical twins, born nine weeks premature and her brain damage occurred day 3, diagnosis is Cerebral Palsy which left her severely affected in her motor skills area of the brain and with Cortical Vision Impairment. She is totally dependent on us and is lucky that she has the support of her family which includes both parents, two older sisters and brother. Her twin only survived 25 hours.

Over the years there have been many struggles which has only highlighted that her disabilities are not the hardest thing to deal with but bureaucracy and the lack of respect between the professions e.g. doctors for therapists, therapists for teachers and least of all for the parents. Each wish to protect their own patch with little regard for the person involved.

We have been lucky to have been involved with Conductive Education programs, the Statewide Complex Communication Needs Project (which was highly successful but unfortunately the SA Government did not adopt the program- once again lack of support from service providers) and therefore we have the support of a group of parents and knowledgeable therapists.

It was difficult during her adolescent years but every now and again there was some support from the service provider. However it is now even more difficult and frustrating as Disability SA seems to think that once a child turns 18, no more intervention is necessary. They will not support communication device introduced by previous Novita speech therapists. There was no hand over been child and adult services. Adult Therapy is not equipped for “hand on services” and do not have skills in Augmentative and Alternative Communication or limited at best.

We are finding that there are no appropriate day options for young adults, which incorporate activities such as assisting people with communication devices [AAC] and switch adapted computer programs, literacy programs for non verbal people and the principles of Conductive Education. The programs visited were very disappointing and with no stimulation or proper inclusion. There are very few options for people in our situation.

There are numerous issues but these are a few of those important to us

- We use a private physiotherapist who has many years of experience with CP and the disability sector. Reason for this is because the lack of ongoing support from Service Providers, we have experienced incorrect ordering and prescription that even though now we are paying for a service we are able to manage our daughter’s physical needs better. We now have support at meetings with Doctors and staff from Disability SA
    - *It is a worry that many are unable to access private therapists and are completely dependent on service providers*

- The training of therapist in University etc seems to be only of a general nature. This has been supported by e-mails I have read from Speech Therapists on the ACOLUG@LISTSERV.TEMPLE.EDU- comments such as: “ As a speech therapist I can tell you that the only training I got in AAC was through continuing education courses and workshops that I had to find for myself. And it was very hard to find any! Most graduate schools offer very little training in this area."

- Even though words such as "social inclusion" & "equal opportunity" are always mentioned by the departments/or service providers there is currently little or no importance put into giving a non verbal disable persons the opportunity to learn communication skills using low tech (PODDs) or high tech (Communication Devices) giving them the opportunity to tell their story or have the community interact with them. It seems that a disable person should only answer when spoken to and then only with yes and no.

- Due to lack of understanding the complexity of "multi-disabilities especially involving CVI", many therapists apply inappropriate methods of assessment. Another situation experienced many times & I do not have the time to expand on the deplorable examples of incompetence. There should be more training and continuing education especially for the therapy managers as it has been our experience that they are not up to the latest in research and world best practices. Not a good situation for young therapists or for the Department Heads that use their advice to help form policies etc.

- Our daughter is unable to attend to any of her personal needs such as showering, toileting, feeding, drinking. She is totally dependent on us and we do not have any support or respite and the only contribution we receive is the $100 a fortnight. From this we pay the physiotherapist, speech therapist, massages and pay for equipment which she requires but Disability SA does not support. An example of this is splinting, which assists in her sitting and correcting her posture, which has allowed for uncomplicated seating to be prescribed for her wheelchair (saving $ and problems in design in seating). We have not been able to get funding from Disability SA so have had to pay for two suits of $2,500 each. This will be an ongoing expenditure for us as the suit is a preventative measure especially as she needs to sit in a wheelchair the majority of the time. She needs hand splints to help with her switching etc

- Day Options for Young Adults here in SA currently are as good as non-existent for the multi-disabled that encourage more learning, stimulation & age appropriate activities.

  We are currently together with friends in similar situation doing home schooling, using minimal resources that we have available.

- Currently our daughter lives with us and we do not know what the future holds as we are also ageing. We want to continue to care for her as long as we can but are now starting to have issues such as lifting. The process we need to go through to obtain a overhead lifter takes an eternity. Our private physio put in a request Feb 2010 and now Disability SA therapists (mid August) wants to establish whether we should have a mobile lifter or overhead lifter even though the application was for an overhead lifter.

Once again due to time restraints, our answer to some of the questions

Who should be eligible?	The wide coverage
Who makes the decisions?	• Individuals with a disability (together with prime carers). • Not the disability support system. • Funds can then be used to purchase individually-tailored services. • Greater accountability for dollars spent if there is a choice between service providers and they would have to ensure better outcomes • There should be an option of roll-over of unused funds to ensure there is money for larger purchases such as wheelchairs, communication devices etc as they all have a limited life and their replacement can be budgeted for and not have a long waiting list
The nature of Services	• Specialised Speech Therapy, access to Medical, Naturopath, Chiropractic etc maybe through Specialist Centres which have good access, good parking and facilities which would include lifters to transfer on to tables etc which would also allow for a person with a disability to be weighed, blood collection. • The centre could also have a gym which has equipment design for the health and well being of the disabled. • Services which are designed for prevention of some of the side effects of the disability instead of just making people just comfortable.
How should people's needs be assessed?	• Ensure the appropriate Specialists have a complex knowledge of disabilities • More training for the therapists involved (someone with some years of "hands-on experience" not directly out of university with a piece of paper and made a consultant. • Knowledge, especially CP with CVI needs an assessment that is a 'work-in-progress" • The data should also be able to be openly challenged
Work Force Issues	• More education & training • A mixture of age appropriate & life experience workers for people with disability • There should be a career path which could entice the better workers to stay in the business
Governance and Infrastructure	• One of the most frustrating things is lack of information that is disbursed. A good example is I did not hear about the meeting at Adelaide Town Hall from Disability SA but indirectly. I wonder how many other people have not even heard about the productivity committee and would have like to respond. • I have been to meetings held with regards to the changes previously made in SA to bring all services under the umbrella of Disability SA where NO minutes were taken of the audiences' questions or concerns. It makes you wonder what information is given to the decision makers and MPs.

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

Make self-management a National Priority for people living with disability