

**House of Representatives Standing Committee on Family, Community, Housing and Youth:
Better Support for Carers Round Table – Adelaide 13/8/08 Jayne**

Our 14 year old daughter has Dravet syndrome, leaving her with an intellectual disability, speech disorder, ataxic walking, behavioural management issues, scoliosis and unstable epilepsy. The level of care she requires and the difficulties accessing appropriate services have created great sadness, stress and frustration for my family and I over the past 14 years.

To imagine what it is like to live with a child with an intellectual disability, consider your own experience as working individuals and parents ... then magnify it ten fold. That is the impact we experience on every aspect of our life.

Quality of life, mental and general health, family enjoyment, friendships, work opportunities, sibling experiences and our current and future plans are all adversely affected by the stress, lack of practical assistance, understanding and long term uncertainty regarding our daughter's care. For example, I face the prospect of dropping a significant portion of my work in the next few years, from our daughter's increasing needs. Once she turns 18 we will have to find new adult medical, disability and respite services – which provide less support than we currently receive.

My husband, a GP, and I as a Diabetes Nurse Specialist even find it hard to navigate the disability support system. We have been forced to work at a high level, inputting into disability policy and service delivery. In the past few years, I have lobbied governments, departments and politicians. I have also produced resources for other parents on what's out there to help and child protection and set-up and maintained an email network to share information with service providers and other parents of children with disabilities. What does this tell us if it is a parent doing all this work?

Deinstitutionalisation closed the services and successive governments failed to provide an effective and integrated system to support our daughter's complex care away from the institutions. We want our daughter to leave home like other young adults. We want to be empty nesters ... something we are terrified will not happen with the current unmet need of parents in the Baby Boomer generation, due to the lack of planning and investment in accommodation. The increasing numbers of children with autism and the influx of higher functioning adults who have until now lived often co-dependently with their aging parents are adding further stress to waiting lists. The failure to plan for the accommodation needs of people with disabilities has created a crisis. It is time to change this.

Support our life by fixing the care delivery system – that more than anything will support us and

- Guaranteed accommodation in our daughter's early 20s, so she can leave home like other children
- Home cleaning and ironing support (like for the aged)
- In-home behaviour management assistance – psychologist currently \$160 per session
- E-based communication/information network for parents of children with disabilities
- State based resource list for parents to find what they need
- Utilisation of the SA produced 'What I want you to know about me!' website care plan resource
- Standardisation of things like medication charts, to prevent drug errors and the filling-in of so many different forms to do the same thing in different services
- Self managed funding system
- A child protection strategy for children with disabilities (physical, emotional and sexual abuse)
- Medicare Enhanced Primary Care health check for Carers item number (health assessment and linked allied health appointments/exercise class vouchers).

Fighting for our family's rights so publicly is an ongoing and significant stress as we have had to tell our story so often in the past 14 years. The grief of having a disabled child never goes away but the burden felt by parents caring for these children and young adults can be lightened. Governments decided, rightly so, to deinstitutionalise all those years ago. We ask that you not only listen to the stories you hear during this Enquiry but that you also ensure a sufficient investment is allocated to put in place practical and sufficient systems that support and value our disabled children and their families. That, after all, was the aim of deinstitutionalisation.

Balancing Work and Life Responsibilities

Carer Story

I am the mother of three daughters. Our middle daughter is 14 and has a genetic disorder causing intellectual disability, unstable epilepsy and a number of associated conditions. I now work from home in order to be able to also provide the care our daughter requires.

I was a Clinical Nurse Consultant of a medical specialty at a major hospital and returned from 15 months maternity leave to my 4 day a week job after our middle daughter's birth. We had employed and trained a nanny to care for our two daughters but she resigned on the first day due to her fears of caring for our daughter. It was obvious I would not be able to continue in my job. I resigned the position and was given one day/week in a position two levels lower. However, the people with whom I was working felt threatened by me still being within the Unit and created an environment that was impossible for me to continue working in.

I developed a business plan to run my own business, in order to work while caring for our disabled daughter. As a nurse this was a unique approach to the challenge as few were working in private practice. I had to think outside of the square in order to consider how I could still work as a specialist nurse from a home base. If I had not done this, I would now not be working. What a terrible loss of skills that have had a significant input into both my area of specialty nationally and the care of people with disabilities.

Obtaining skilled child care has been a constant challenge. Using a child care centre was not an option, so at the time I negotiated for my mother to provide some informal care and I cared for our daughter the rest of the time, juggling work and child care at home while building up my business.

Now that our daughter is 14 it has been getting harder and harder to keep trained care workers to provide us in-home support and respite care at home. I receive 2 hours assistance from the local council and we have had a great deal of trouble getting appropriately trained staff, especially with Sarah's epilepsy. Eventually we had to change agencies – to one that is significantly dearer – in order to get the appropriate care for her. We have had care workers who have seen Sarah have a seizure and then will not come back again as they are too scared. Funny, I thought that was what they were being employed to do – care for our daughter and her associated problems.

The turnover of carers is enormous, which makes it stressful in itself. You already feel like you are living in a gold fish bowl let alone having to have a steady stream of new people coming through your home. Most of the carers are not skilled enough to deliver the care we require and I have to do extra training and emotional support of them!. Some agencies employ a lot of students or people looking to provide care for a short period of time, before moving onto something else. This increases the turnover issues.

A few years ago I had a care worker – an occupational therapy student – bathing my daughter. Our daughter started to have a seizure in the bath and I had to rush in and train the care worker on what to do. I am being offered a service that is not a service. The whole first aid training is inadequate because they are not doing it around the lived experience of treating a seizure e.g. in the bath. They need much better training

videos showing children having different types of seizures and practical suggestions of what to do in a variety of circumstances.

We are told it is very difficult to get care workers. They are certainly not equipped to manage our daughter's behaviour, as she has a lot of autism-like behaviours – quite complicated. There is a need for a pool of higher paid/trained care workers.

What am I going to do once our daughter turns 18 and many of the services she accesses now are not available? Three of the four respite options will no longer be available. When she starts post-school options, currently there is no transport. I will have to drop her off and pick her up each day, which will take 2 hours every day. There goes my life: how am I going to work? What a waste of my professional skills which are currently in short supply around Australia.

I often spend time crying and worry about what happens if I get sick or worse still, die? I am exhausted, sad and scared. I have no family back-up so we have to import the care we need. Juggling my work and family commitments is increasingly difficult.

I don't feel confident even taking my daughter to hospital as our experiences there have not been positive. As a health professional myself, I provide a high standard of care in what I do, but we can't find it in return for our daughter. There have been two mandatory reports made regarding physical abuse our daughter experienced in 2006 and she has often returned from places bruised. In order to use the care we require for me to work, we have to trust it. There are many issues requiring attention to improve the work/life balance of carers of children with a disability.

Why should I have to work at such a high level of advocacy in order to evolve the services we need to ensure my daughter's future? I would spend about 14 hours a week in disability advocacy and helping to evolve the services we use and that is on top of the care we provide for our daughter and my work. For example, I have set up an email network to provide adequate information for others, do these submissions, and work with the organisations to improve their service delivery etc.

Professionally I see a lot of patients with intellectual disability and their parents. A lot of the work I do initially is to help them sort through the disability service quagmire as I can't help them with their health issues until we have sorted out these other more pressing stressors.

The skills and money people get from work provides parents with increased options in dealing with their child and their disability. It also leads to more sophisticated ways of operating with service providers. Equally, the more parents of children with disabilities are in the work force, the more we evolve community understanding as a whole. It also provides 'respite' from the role of Mum and Carer and provides a sense of achievement and self worth.

To continue to work, parents of children with disabilities require the government to sort out the disability support system. Due to our experiences with our disabled children, these parents are often highly motivated and have enhanced skills that are valuable to employers. Their tenacity and determination should be prized and supported.

August 2008 – Jayne

South Australia

Healthcare of Carers

It is well known that the health and wellbeing of Australian carers is significantly lower than the rest of the population. I would like to make some additional suggestions for the Enquiry to consider in their deliberations on how to better support carers. I provide these suggestions from both my experience as a Diabetes Nurse Specialist in private practice with a clinic in General Practice and a carer of our daughter who has Dravet syndrome and requires a very significant amount of care. Also, my husband is a General Practitioner and I consulted him on the viability of these ideas.

The introduction of a new Medicare Item Number, Carer's Wellbeing Check, for GPs to provide a health check for carers would provide a new tool for both GPs and carers in Australia. While there are a number of Enhanced Primary Care item numbers that various carers would be eligible for (e.g. GP Management Plan/Team Care Arrangement if they have a chronic health condition requiring a team approach to care and the Mental Health Plan if they have a depressive/anxiety based condition) to have a specific item number and process designed for the specific needs of carers would increase the uptake of the item. This could include a general health check, and mental health assessment for issues carers are known to be at high risk of e.g. stress-induced problems, review of bloods, risk factors for cardiovascular disease. It would be good to add to this either vouchers for allied health professionals and/or exercise classes to assist carers to address their health risks (e.g. obesity, cardiovascular risk factors).

Doing the Carer Wellbeing Check would also enable the GP to identify other health issues for which other plans could be done, in order to access other health professionals e.g. Mental Health Care Plan.

Connecting with Parents of Children with Disabilities

Getting information to carers can be a great challenge. This is especially true of parents of children with disabilities. Our own experience highlights this, considering our daughter had her first seizure at 5 months of age and we had a number of admissions for prolonged seizure but did not get told about or referred to any services until I self referred to Novita Children's Services when she was 3. We had even had a retrieval via helicopter, visit to intensive care and a number of hospitalisations during this time. The lack of information made our journey even more difficult and we have heard so many similar stories over the years that we are not an isolated case.

We also had trouble accessing support when it came to start Kindy as, once again, nobody told us there were support services available until I rang the Education Department and asked for the 'Special Education Unit'. I was fortunate to call the day before they were to allocate their Access Assistant services. So I asked them to fax me the form, I filled it in and then was eligible for a full-time Access Assistant for our daughter's time at kindy. Equally we were not told about the special kindy that we would have chosen if we had known about it.

As a result of these experiences, we feel there is a need for a package of information to be produced that includes basic information to enable parents to link with the services they require. Additionally there should be information on how to 'case manage' your child in order to get the best outcomes, how to get the most out of your

GP and Specialists etc. Contact details are also required for a range of services they might need. Ideally there would be input from some parents, with quotes from them to 'mentor' new parents.

This could be provided by either a GP or General Practice Nurse, as all of these children would have a lot of contact with their GP. We would also encourage either a payment apply for this service, to reimburse for the time involved and to reward the general practice, providing further motivation for the uptake of this service. This would also create a database of people with children with disabilities that could be further utilised to directly communicate with parents on a range of issues.

Consideration could be given to providing Practice Nurses, via Divisions of General Practice, with additional education and support to provide this service with, or on behalf of, the GP.

I have provided you with a copy of both the child protection booklet and resource directory I have done here in South Australia as examples of approaches that could be considered in the production of the resource.

I feel there is a need to bring together a targeted group of people to consider the health issues of carers and the development of the resource I have outlined above. I would be happy to be involved with any future development of these resources, given the experience I have had here in South Australia.