PERSONAL RESPONSE – THE REGIONAL DILUTION EFFECT

As the mother and primary carer of a 23 year old disabled young man**, who cannot represent himself,** I wish to submit to the Inquiry into the National Disability Insurance Scheme that I believe that such a scheme must include

- **Attention to regional issues (services, supports and infrastructure)**
- **Flexible respite (facility based or in-home)**
- **A system that meets the needs or people with a disability and their families and is not crisis driven**
- **A system of CHOICE for their needs driven by the individual and their family**

Tom, our son, has cerebral palsy and a significant intellectual disability. Tom is relatively independent in some of his needs, totally dependent in others.
The past 23 years have been a huge journey for us, because living in a regional area DILUTES everything whilst it CONCENTRATES to cost to families of having a child or an adult with a disability.

This is a synopsis (aka reality check) of caring for a child/adult with a disability 300km from Melbourne.

- Lack of specialist services
- Cost of travelling to appointments out of the region to families who can least afford it
- Accommodation costs associated with appointments out of town
- Lack of choice – of schools, services, carers
- The long and frustrating fight for every bit of integration funding throughout kindergarten and school – those supports not being adequate for the needs of the children
- Lack of services for challenging behaviour
- Waiting lists for the Disability Service Register
- Interminable waiting for Individual Support Packages (How many ISP's have been allocated in this region as opposed to the waiting lists?)
- Poorly resourced DHS services in town – staff are overworked to the max and unable to provide a SERVICE that addresses the needs of our families
- Lack of respite options and worse still......
- Lack of **flexible** respite – allocation of weekends a month before it is scheduled, no opportunity to book a person in for a specified date, giving the family respite when they really need it (UNLESS IT IS CRISIS DRIVEN)
- No suitable supported accommodation options
- A system that is crisis driven, and not responding to the needs of families who have chosen to plan a future for their children/adults

This is where our family is at:

- **Respite: current services do not meet our needs.** Tom is able to access disability respite services in our area. However, because of the nature of the current system operating in the facility based (overnight) respite services, we cannot request a weekend when respite is needed.
- **In home respite:** we have a qualified carer **of choice** who can provide excellent quality care for Tom at home if needed. We cannot acquire funding to assist with this through Making a Difference as she is not affiliated with any service provider. Where is the choice in that?
- **ISP planning:** Our family created a 'plan' for Tom in late 2009, which helped open our thinking in terms of Tom's future. This creative integrated approach is a good process but we are not yet on the DSR let alone anywhere along the track with an ISP. We cope but what about other families?
- **Shared supported accommodation:** a group of parents is very keen to pursue shared supported accommodation for our 4 adults, all good friends. None of the young adults have an ISP, nor are registered on the DSR so what hope do we have to attain the level of care they need to live a fulfilling and independent life? There is no-where to live at present in Horsham.
- **Carer Services:** until payment for carers is raised to a reasonable level, we are subjected to decreasing quality of service, lack of initiative and inadequate care. It is difficult to justify having a carer who is basically just a minder. There is a HUGE difference in the two.

It is enormously frustrating as we recognise that we need to plan for Tom's future, that 'the disability system' has been unable to respond to our needs, by providing **planned** support along the way. We have certainly had our share of issues with appropriateness and availability of services over the years, but we have always known that Tom would require supported accommodation and whole of life support when we can no longer do it.

The message that comes through loud and clear, above the access issues, community attitudes, uphill battles for equipment and services, accountability/transparency issues, is that there is an urgent need for dignity for people with disabilities and their families. **The system needs to be flexible and responsive to individual circumstances.**

The System:

Simplicity, choice and control:

- Families/people with disabilities should have the choice to be supported to control their funding with **a highly skilled, well resourced advocate, independent agent or service provider** in a long term support role.

Services and Delivery:

- **Waiting, waiting, waiting:** Most services currently in use in Victoria have waiting lists reflecting the inadequacy of the system.

Dignity and respect: are basic human rights .

Making it better:

- Less consultation, more action (how many accommodation inquiries does it take to determine the needs of people with a disability?)
- Single entry point and standard assessment tool;
- Recognition of the importance of the role of care staff in the lives of people with a disability and their families/carers with wages that reflect that required level of skill, initiative and dedication.
- Early intervention is vital to enhance the opportunity for people with a disability to live to their maximum ability, whether the disability is acquired through birth or injury. Early intervention should be a part of a **whole-of-life support plan**.

As a family we totally endorse the National Disability and Carer Alliance in their recent media release:

"The current disability support system is unsustainable and indefensible. It is chronically under-funded, inefficient, inequitable and, most seriously, fails to meet the needs of Australians with a disability, their families and carers. Unless there is fundamental change, the gap between the need for disability services and their availability will grow.

The reforms, most importantly the introduction of a National Disability Insurance Scheme, should create a system that is equitable, efficient, sustainable and based on self determination. The person with a disability, their family or carer should be placed at the centre – exercising choice, control and receiving the services and supports they require for as long as they require them."