SUBMISSION TO THE PRODUCTIVITY COMMISION

Date: 14th June 2010

Introduction

We are the parents of a 33 yr old person with a genetic abnormality, not fully diagnosed. The abnormality has presented with moderate to severe intellectual impairment, severe communication deficit, skeletal problems requiring major spinal surgery to maintain mobility and internal organ function and compromised kidneys which may cause renal complications. In total, full 24/7 care is required. At no time can this person be left unattended. Currently there is no individual funding in place nor is there any prospect of same, even though accommodation is through a service provider. A block funded day service is accessed.

Over many years we have been active in support organizations and advocacy so our experience encompasses more than our specific family situation.

The current system:

In a word the current system is broken and so needs major adjustment or totally replacing.

- Currently the system is inequitable across the states and inequitable within Queensland. It is well known in Queensland that the 'squeaky wheel gets the funding'. This has led to astute parents overstating their need for assistance and receiving support beyond that which is equitable compared with others. There is also evidence of deliberate false diagnosis so funding becomes available especially for support in education. Many funding packages in Queensland are not subject to review. There are instances where clients exiting institutional care have required large packages which no one begrudges. However, as they adapted to life in community, developed socialization skills and self care skills, there has been no review of the size of packages. Consequently it appears to those who do not enjoy funding that there is an inherent inequity in the system.
- Paperwork is the bane of both service providers and families. We have been told we need to update our application for funding even though there is no prospect of a success. This process takes quite some time, requires that we paint ourselves as incapable, requires service provider time with no provision for recompense. The application will need to be vetted and entered into a database, thus using bureaucratic time with no direct service provision.
- Legislative compliance: Service providers spend a large amount of time in paperwork to comply with legislative requirements. e.g. Fire Prevention and Restrictive Practices Legislation. Often, the process is cumbersome and has unintended consequences that increase the administrative load with no clear improvement in service provision for the clients. Much of the quality assurance measures are not of consequence to clients and families, yet valuable administrative time is spent in compliance. Reporting processes are often repetitive

across jurisdictions and across individual grant monies within jurisdictions, multiplying the cost.

- Parental provision: When parents have made judicious investments in the name of the disabled family member there is a major disadvantage in the effect on the pension entitlements for the client. This becomes a huge mistake. The Special Disability Trust has made some allowance but there is no provision for accumulated monies in the clients name to be placed in these trusts. Generally the accumulated funds are resultant from bequests, often small, made before these trusts were in place. Nor is the Special Disability Trust viable for small amounts of capital that are still of a size to affect the pension entitlements. The message for parents is make no provision for your family member unless you have the capacity to provide considerably.

Question	**Your suggested solution**
Eligibility	
Who should be eligible for disability support?	50 years ago, few women worked, people with a disability predeceased their parents and society had an expectation that parents would support their family member for the term of their life. Now, most women work, people with a disability are highly likely to outlive their parents. Society still expects that parents will support their family member for the term of their life. Society will provide should the parents be totally unable to cope and after the death of the parents. However, both the parents and the person with a disability have an entitlement to, at least, an average quality of life which allows them to participate in the community. Consequently all people with a disability are entitled to a basic level of community support through funding. There are two distinct classes of disability: life long disability and acquired disability. Those with life long disability have little chance of ‘repair’: but they have an entitlement to therapy services, respect and a caring environment to develop their full potential with support systems to protect their vulnerability. Those with an acquired disability are entitled to automatic rehabilitation services through a service such as Commonwealth Rehabilitation Services. There was a time when all were eligible for these services rather than the current system of only those clients on Centrelink benefits being able to access the service. With comprehensive therapy services, those with an acquired disability can learn to function as closely to their full capacity as possible in their

	new circumstances. Once stabilized, the client then moves into the same umbrella as those with a life long disability. Once diagnosed, all client details should be available through a centralized database open to all service providers registered as needing the information as well as government agencies such as Centrelink and Disability services both State and Federal. Assessment instruments should be common across jurisdictions and service providers to eliminate the need for multiple assessments, recording and updating.
How should a person's situation be fairly assessed?	There are two components: actual degree of disability and capacity to support within the environment of the person with the disability. The degree of disability is sometimes not totally objective especially where psychiatric and intellectual capacity are involved. This needs to be gauged by a team comprising medical and therapeutic professionals. The environment and capacity to support is subjective and fluctuating. Information needs to be garnered from any reliable sources and subject to review with options to either increase or decrease. Currently in Queensland if you can cope you do not get a package; if you don't cope you are more likely to get one; if you say you can't cope you will.
Funding	
How could a new scheme be financed?	Through the taxation system. There should also be a 'no fault' system to reduce the high costs of pursuing claims through the courts. Currently much of the claim settlement monies goes into the legal system with little outcome for the person with the disability. There should be tax incentives for individuals and the corporate sector to contribute. Parents who provide for their family member should be rewarded through the taxation system so other family members and their own retirement is not compromised. There should be incentives for families to provide the extra support in a volunteer capacity, possibly through the taxation system. Siblings and friends could be 'rewarded' by flexible eligibility to student study allowances in lieu of seeking paid employment thus making their time available for caring roles. Similarly there should be disincentives associated with overstating the need for support, possibly a 10% reduction in actual funding for clients whose needs are deliberately overstated.
Who the funding provider should be?	A national scheme has to be administered and assessed Nationally. Other authorities should fund and administer programs specific to their jurisdiction e.g. accessibility to public transport.

Services Needed	
What are the specific services that you need more of?	Our daughter lives in a residential environment with no funding package. Her parents provide support on a very regular basis for all her medical and dental needs and to facilitate her quality of life beyond the means of the service provider. Therapy Service (Psychology, Speech Pathology, and Physiotherapy): In many instances, especially as the client with a disability ages and exits the school system access to therapy services becomes very difficult. Many service providers are not in a fiscal position to provide therapy services especially when there is so much legislative compliance required. The load falls to parents and the Medicare system. However, even when the provision of therapy services is economically viable it is extremely difficult to find therapists with the expertise. Surely, a person with compromised communication has a basic entitlement to access any services that can offer systems that can facilitate and enhance communication and so reduce anxiety and improve the quality of life of the client and those sharing that life.
How can current services be improved?	In a word, they are totally inadequate. Most existing services are of good quality but there are insufficient of all types placing huge stress on families because of uncertainty, especially at exit from school and as parents age. Dental services are unsatisfactory. Dental health is fundamental for general health and wellbeing. The public system has let us down badly. The private system of preferred providers is counter productive as most dentists do not provide the anesthesia services required.
Is there an alternative service option that you see a demand for that is not currently available?	Community living options, with live in support persons, in a cluster setting. The constant parade of different support workers in and out of residential does not create a manageable, consistent dynamic. Remuneration for support workers is an issue. There needs to be balance between professionalism and the loving caring of an uneducated support worker. Support worker training needs to be consistent nationally with several levels of support training: • Compliant with all legislation; • Compliant with legislation specific to the care provided; • Compliant with fiscal and medical arrangements specific to a client; • Caring, loving support. There needs to be a sense of professionalism and a recognition of the value of the clients and the support workers. Our society needs to

	start to value people and the people who care for people.
A New System	
What would be the least disruptive way to introduce a new system?	There needs to be a transition period where existing arrangements co-exist with new arrangements as new arrangements are progressively introduced to new recipients. Old arrangements can then be reviewed to make them consistent with the new arrangements.

Sincerely,
Alison and Bill Semple