Submission to the Australian Government Productivity Commission

Disability Care and Support Inquiry

Who Are We....

Redland District Special School is an Education Queensland funded school for students with high support needs whose educational requirements cannot be met in a mainstream school. The school currently includes an Early Childhood Development Program which provides support to parents in the form of playgroups and educational programs from the age of 2yrs. All students attending the ECDP and the school aged programs (6-18 yrs) have their disability and adjustment needs verified by Education Queensland Guidance Officers. Students have a range of disabilities, but all are significantly intellectually impaired, while many also have a diagnosis of Autism and some have physical and mobility challenges. Almost half of the student population is non-verbal, with 25% of students requiring emergency health plans for medical conditions such as epilepsy.

This submission is from the parent body of RDSS. Parents of this group of students experience daily the frustration and sense of abandonment that those caring for children with disabilities experience in Australia at present.

Our Submission

We are a group of parents whose common experience of trying to do the best for our children is representative of the current Australian situation.

Our submission is not about how education meets the needs of our children.

Our submission is about how to improve our ability to provide quality care for our children now and when they become young adults, without destroying our family units, marriages and careers.

Currently We...

As parents we jump through hoops telling our story to Disability Services Qld, Centrelink, the medical profession and educational providers over and over. Funding for support from DSQ is only now available in blocks so after each block parents have to beg for more support, that is, if we are even successful in the first place.

Moreover, parents and families of children with a disability experience great despair, anxiety, and feel isolated and alone with the lack of adequate support structures.

There is no continuity of service and the process of continually applying and reapplying for pensions, respite, mobility aids, therapies, medical aids wears us down. This is compounded by the absolute rejection of applications for support, even when families are desperate. It is commonly known that if you appear to cope, you will not get any assistance. Support is not forthcoming unless you have reached crisis stage and even then what may be a crisis to each family, may not be considered enough of a crisis to receive support or funding.

Quality of family life is not seen as a priority. Often the support that is given is miniscule and goes only a tiny way to helping families cope.

Our submission
We fully support the introduction of a National Insurance Disability Scheme to better fund support for those with disabilities.

Issues

Federal vs State Management- Lack of a national approach to disability services and the provision of such. Currently each Australian state has its own government department managing disability support. A student who transferred to Qld actually went back to Adelaide to collect his wheelchair which he had been waiting 2 years for, rather than face starting to wait another 2 years to get a wheelchair in Qld.

Suggestion:
A national system of registering as a person requiring support is needed. Similar to Centrelink, once the diagnosis and verification of disability is made, that should be it. Families should then be able to apply for whatever support e.g. respite, mobility aids, Therapies, medical aids without having to re-tell their story.

Service Providers
While they do a great job, the **management fees they take appear excessive**. When families are given support, it disappears very quickly with the management costs of service providers brokering out to other services to deliver the actual care.

There **are never enough providers in our area**. The common need for parents of children is respite. Families love and care for their children, but these children require 24 hr care and siblings especially need attention too. Respite providers are scarce and waiting lists long. Again students are given a block of funding and when that is finished so is the respite, until families apply again. Families need ongoing familiar, competent carers providing respite long term.

Families also need suitable outside of school hours care and adequate facilities to cater for this. This service would allow parents to return to the workforce and may have a positive impact on the overall well-being of families on a financial, social, and emotional level. Currently, there are limited places for children with special needs in outside of school hours care facilities. The legislation that these facilities and individual workers adhere to is the Child Care Act 2002. This legislation caters to the needs of young children and yet it is utilised and applied to all children in outside of hours school care facilities, regardless of age.

Suggestion:

The system where service providers gain access to funding needs to be monitored and reviewed*. It is difficult for them to provide quality care when they can't guarantee job security, if they are depending on applying for grants to run their programs for the next 6months or year. Training of staff is therefore almost impossible with the insecurity that exists around funding long term.*

Early Intervention

Certainly the federal government has acknowledged the immense impact early intervention can have on the impact of a disability such as autism. However early intervention seems to be losing its priority. Programs such as Applied Behaviour Analysis (ABA) make huge differences to students with Autism and parents have taken up the opportunity to use the federal funding for such programs with great success.

Access to such funding is still difficult to receive as it is only available through approved autism advisors at Autism Queensland. This in itself can be problematic and is frustrating for families whose particular situation is not catered for due to loopholes with the current policy framework. The *Helping Children with Autism* initiative is welcomed, however much more needs to be done.

Suggestion:
This needs to continue. The provision of services at an affordable level so that all families can access intervention, especially if they are on low incomes. Provision of early intervention for any child with a disability and not just autistic spectrum disorder.

After School – Young Adults with Disabilities

It is common knowledge that once our students leave school, our lives will change again. Many mothers have to give up employment that has been manageable only because their child was in a school program 9-3pm. The anxiety around what comes after the school years is enormous. The process of applying for post school funding grants needs to be changed. It is another juncture at which the family have to plead and beg, retelling their story and then waiting anxiously to see if they have been lucky enough to get funding so their child can attend a post school service for a few days per week.
For those young people who might be able to gain part time supported employment (open employment is just not feasible for our children) training needs to be available.

We are aware that the Australian Qualifications Framework is implementing a national framework to align all states and their systems in terms of educational qualifications, however in practice, the system does not adequately cater to the needs of young persons with a disability.

In Qld we have had the “Smart State” agenda- where does a young person with an intellectual impairment fit into this agenda? The “Smart State” agenda is

concerned with creating citizens who can contribute economically to society yet how are persons with a disability able to achieve this outcome if the institutions that provide such services are not fully supported by the government. TAFE colleges have to prove their academic results in order to retain funding for courses- so those who aren't going to contribute to this agenda are left without relevant training opportunities. We are told that to run courses for those with disabilities is too expensive and the outcomes not as measurable.
The message we receive is that people with a disability are not valued nor are they worth spending money on.

After school where do our students live? This is a huge area that needs a complete overhaul.

Families apply for Family Lifestyle Support Packages so that their young person can afford to share housing with other young people with disabilities. This sounds great but for the fact that practically no one receives this funding!! Families apply and reapply for years to receive this funding, most never actually receiving it.

So when parents of those with disabilities tell you that it is a “birth to grave” job to care for their child, it is absolutely true. These parents forego what might be considered a “normal life” and sadly accept that their life will never be the same.

These young people never leave home and live independently with support. It just doesn't happen for most- not in Brisbane. The issue of aging parents struggling to maintain their adult child is a critical one.

In Qld the pressure on families often results in families making the heartbreaking decision to relinquish their disabled child or young adult to the Dept of Child Safety or DSQ. This puts further pressure on these agencies to provide support that they are not really equipped to provide.

There are plenty of suggestions around how to improve this e.g. urban villages, using the aged care residential models of independent units etc..,

What needs to stop is the placing of young people with disabilities in nursing homes. Families who can't cope with multiply impaired, high needs students in desperation agree to these placements. The Youngcare model in Brisbane is a small ray of hope on this front.

Suggestion:
Both of these post school issues could be resolved by a national system of registration for those with disabilities and a national system of allocating funding to approved and accredited service providers for training and long term accommodation. An accreditation system similar to the aged care model might be employed. Service Providers would then be able to develop a range of housing and accommodation models to cater for the levels of support required.