Submission No 3

INQUIRY INTO TRANSITION SUPPORT FOR STUDENTS WITH ADDITIONAL OR COMPLEX NEEDS AND THEIR FAMILIES

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Feedback: Social Issues inquiry – children with significant complex issues

Dear Dr Groves,

I would like to make the following comments for this submission.

My background: I have a 14 yr old son – Stuart - who has spastic quadriplegic cerebral palsy (needs pushing in a manual wheelchair), epilepsy, no speech, and severe intellectual disability.

I work within a DEEWR funded DES provider both with DES and TTW clients and assist with vocational development and creation of long term employment opportunities for people with multiple disabilities (the hard cases).

I moved my son at the beginning of this year from the private RIDBC Alice Betteridge School across to the NSW Dep Education State school - Sir Eric Woodward - where my son would gain regular access to hydrotherapy services as the charter/profile of the RIDBC ABS school had changed over the past few years and services eroded despite lobbying from school community up to the board level. You can't fight city hall.

Our life: The NSW Dep Education special needs transport system wheelchair bus (a modified tpt van) picks up my son (after picking up 3 other kids on the run) at 8.30am and takes Stuart up to St Ives Sir Eric Woodward for 9am start.

Whilst at ABS RIDBC we were always picked up by 7.30 am and never dropped off before 4.30pm due to travel times/distances and the way the runs ran.

On Wednesdays Stuart catches a modified van/Bus from St Ives SEW to Allowah Presbyterian Childrens Hospital – Dundas - where he stays regularly on Wednesday night throughout school term as a respite night.

For families with complex multiple issues respite is a normal part of their life ensuring that families keep their high needs children at home with them rather than them breaking down under the stress and dumping them off at the hospital or police for relocation as there are no long term options accessible for parents.

I have no additional familial supports in place and quite the contrary intermittently am called upon to provide additional supports to extended family members. (The cry of the middle generation caught caring at both ends and trying to work to pay off the mortgage.)

On that point parents do not know where and when their fast approaching adulthood children (who are really mentally aged 2/3 and still in nappies or are severe mental health cases or multiple disabled) will live is very hard as many parents age faster than the norm due to the demands of looking after a high needs kid.

If a parent has cared consistently for a child to adulthood than why can't we as a society come up with some sort of relief for the parental role.

But here I digress again – another worry for me personally is that a lot of wheelchair people are significantly low in Vitamin D (not enough exposure to the sun) and so likely to get weak bones and be more likely to have breaks – another worry.

Also access to appropriate dental hygiene is absolutely appalling with it being at least an 18 month wait list out at Westmead hospital to get seen. My son had to have 7 baby teeth removed (he is 14 and had a double set and so looked a bit like a shark and also had serious decay in a molar – but he would bite the end off a needle)

Ongoing nutrition intake also being a constant worry due to ritualistic food preferences.

Stuart returns home on his normal school bus to us on Thursday pm. Presently the bus driver takes in Stuarts incontinence products (he is double incontinent

- adult nappies), and standing frame into school on the bus for me when needed.

It would be great if Stuart could access therapy services as an outreach such as serial casting for his wrist and ankles as currently we travel out to Westmead hospital to have this done by hospital therapy staff – they are lovely people. I take time from work and have a sympathetic employer.

It would also be great if OT's, Physios and Speechies could be more involved with the school to consult with staff, teach staff, develop programs to maintain physical well being as much as possible throughout education.

It seems like kids get lots of attention when really little and forgotten when adolescents. Also behaviour management support to teachers is vital. Teaching disabled kids about sexuality and appropriate behaviour and strategies for parents and staff to deal with socially situational non acceptable behaviours.

Special transport services, respite services, Enable, education system, intervention therapy services such as OT, Physio, Speech Therapy, etc and vacation care/oosh care; transition to TTW or DES services all need to be carefully thought out for families with complex issues.

Also counselling for families to be able to accept realistically what their children may be capable of / or not.

Universal electronic education card linked into Centrelink Reference Numbers which electronically records childs needs and supports put into place each year would be great. For example I have a girlfriend who has a daughter with milder cp who attends a mainstream school and each year the mother has to march up to the school to provide "educationals" to the teaching staff on correct positioning of her child, locating her child within the classroom, and tips on how to interact with a tri-diagnosis of cp, autism and epilepsy. Needless to say my friend is totally worn out from the inaneness and insanity and is so over it she is quite bitter and sometimes displays herself unseemly behaviour in response to the stresses shed is under – not pleasant for anyone.

Ditto that the insanity of having to re-educate new staff each year on correct postural handling/or feeding requirements/or medical requirements/

educational requirements of particular children within mainstream could go onto a card and reviewed annually like an IEP in conjunction with education/support team and parents and ensure everyone has access to the information. Just think – what a potential time saver.

This would also be assistive to TTW and DES when time comes to working with young adults to review strategies used to assist and maintain postures, and behaviours etc and provide an electronic case history for service industry and successful strategies implemented and those strategies which have not worked.

Yet I remain hopeful that adulthood for my son will see him with somewhere to live – with others the same that he likes being with and doing things he likes - like seeing music performances(he doesn't care whether the Wiggles or the Sydney Symphony rehearse as long as its live) and engaging with people – he can't talk but he likes being around people and working (I haven't figured this 1 out yet but hoping I will when the time comes).

The left hand needs to talk to the right hand to take a bit of wastage of resources out of the system I strongly feel.

The regularity of medical assessments as requirements for additional funding and support of student – how much is 2 much. Suggest entrance phases: kinde, early primary, late primary, early high school, late high school but not annually – waste of tax payers money.

If a child is eligible for a Centrelink Carers allowance and Medicare Information such as CAS (Continence assistance scheme funding) i.e. dsp eleigibility in the future than surely the state system could utilise this linkage and knowledge base rather than require families to get duplicates of reports to establish merit for service.

Somehow I suspect there are so many layers of beaucracy that I wonder the creaking beast manages to work effectively at all.

Suggest making sure each special needs school like Sir Eric Woodward, Fisher Road, Arrounbai etc all have OOSH or access to OOSH/Vac care arranged as many families have both parents working. The fact they don't may well see the Anti discrimination board called up to review this.

The fact that many special needs children can not access OOSH/Vac would ensure equality of treatment of all children and therefore equality in terms of parental access to services.

For a new family just about to enter a child into school the ability of early intervention support staff to work with children whilst at school would be extremely beneficial as many special needs children fatigue very easily and whilst they are at school they can be batched up according to need.

Review other state education system programs as on grapevine I've heard that Victoria and QLD developed some good ideas for children. Why reinvent the wheel. Review cross regionally what the special need schools are doing and cross regionally implement where relevant.

Have a cross regional events day where all children from these really high needs special schools get together for parents and kids and arrange for the Community Access Programs and adult options to be there so parents know where there children are likely to progress across to and that there is choice open to them.

Also when I applied to change schools the process was very tiresome, repetitive, cumbersome and antiquated – Suggestion: To make forms user friendly and electronic and perhaps link straight in from Dep Health records for diagnosis and intervention service history.

Finally ensure each child has prior to leaving school a CRN number and JCA done via Centrelink as the time this takes to sort out with Centrelink once kids have left school has in some cases taken in excess of 10 weeks.

Finally I don't mean to whinge, and I come from a hardworking background. I am happy to do my bit and continue to work until I'm 65 to pay for my home and retirement – I am just not quite sure how it is all going to fall into place yet as I don't have all the answers.