# DISABILITY CARE AND SUPPORT INQUIRY

We are the parents of 2 children with special needs, albeit incredibility different special needs. As such we have a vast range of experience dealing with the availability, accessibility and affordability of a large range of needed services - or more accurately, the huge non-availability, inaccessibility and non-affordability of vital services under our current disability maze which is convoluted, multiplicitous, fragmented, bureaucratic and inefficient.

At the moment we are accessing over 10 different service providers (Moira, Yooralla, Royal District Nursing Service, Centrelink, Carer Respite, a non-profit respite home, Victorian Aids and Equipment Program, Australian Hearing, a specialist school program for the deaf-blind, 2 different continence schemes – although 1 was just streamlined with Medicare/FAO-, and a domestic childcare provider) *along with* privately accessed mental health specialists for long-term counseling, a private compounding pharmacy and private funding for equipment and attendant care[1] for 1 child alone, each for a different range of treatments/care that are all vital to our child's health, safety and well being. None of these providers include the additional and ongoing direct medical care accessed from an entire team of specialist doctors at Royal Children's Hospital, through our GP and others.

Each provider is dedicated, helpful, well-meaning and caring. They all go out of their way to provide what is within their limited scope. With that said, we have a HUGE shortfall in the true cost that is involved in maintaining either of our children, let alone both of them. Every agency and provider that we use has a different sent of rules and regulations as to what each will/won't provide; what each can/can't provide; what insurance provisions each has/doesn't have; the time limit of each service. Each provider has their individual annual review, their individual rules and their individual paperwork.

As such, we are ardent supporters of a proposed National Disability Insurance Scheme ("NDIS"). Se strongly hope such a scheme would streamline, consolidate, simplify and maximize vital services for the disabled, while at the same time, offering some equity of compensation with those who have acquired their injuries on the roads, or through other currently legally compensable avenues in Australia. We envision that this scheme would be a proactive entitlement to the disabled, versus the current utterly under-funded and manifestly unfair crisis driven "system". We envision that this scheme would help restore dignity to the disabled and bring some sense of normalcy to their families and primary carers so that family and carer breakdown is substantially minimized.

We strongly believe that a comprehensive and assured entitlement to all the services required by the disabled would go a very long way to relieving individuals' as well as their families' onerous administrative burdens, stress and uncertainty. It would provide greater dignity and peace of mind unlike currently where the disabled and/or their families need to beg and plead *for the provision of only some* of the necessary services they require.

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[1] We formerly utilized the equally wonderful services of Noah's Ark, Child Specialist Services, RVIB, and Malvern Special Needs Playgroup as well.

While we can't purport to outline an entire new system from our limited knowledge and perspective, following are some of our key concerns and thoughts.

**Eligibility** – We propose that there be one national system of eligibility that would eliminate the sometimes conflicting definitions between national, state and local systems at the moment. We propose that all those that are deemed disabled by an appropriate doctor be covered from birth –death[2]; whether it is a physical handicap and/or a mental handicap.

With that said, we believe there should perhaps be 2 tiers- one for those diagnosed by an appropriate doctor as having a permanent disability; and one for those diagnosed by an appropriate doctor as having a temporary disability.

**Power –** If they have the mental capacity and are over the age of a minor, those with disabilities should have the power to administer their entitlement once decided. Otherwise their parents or guardians should have that power. This would help facilitate the provision of services in the quickest, most flexible and most targeted way, where those who need the help and their families can choose and implement what they need the most.

Perhaps as a means to help oversee the funding, if funds were ever distributed directly to the individual, those funds could be credited, and then debited for their authorized purposes, from one designated account.

## Services that are Needed

We propose that each individual receive ONE case manager within the NDIS who can oversee and help coordinate all aspects of their care and that all case managers be employed directly by the NDIS. With that said, it may be more appropriate to have 3 or 4 different age-levels that case managers specialize in – i.e. from birth – 6 years old; from 7-21 years old; from 21-65 years old; and for those 65 and older and continue for the entirety of their lifetime. Hopefully it would be much easier to coordinate a systemic, organized and thorough handover within this one agency, as individuals progress to each new age level. This would help provide equity to the disabled, who at the moment are provided different advice and different services from different agencies, and are bounced from plan to plan. Theoretically these case managers would then really know what their client's true and long-term needs are.

We suggest that ONE care plan is drawn up annually (unless warranted earlier), and that ONE Behavioral Support Plan (where necessary) is drawn up annually (unless warranted earlier) that is portable so that each individual can take that plan to their required service

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[2] A cogent example of a problem in this area regards hearing services for our deaf child. We understand that until age 21 coverage is provided (by Medicare ?); and then as a pensioner coverage would again be provided; however there currently is no coverage for the intermediate years.

providers. We also suggest that there be ONE standard set of rules and regulations governing each of the numerous service providers, i.e., autism is recognized as a disability across the board; all agencies providing care under the NDIS should be insured and trained to do PEG feeding where required, or administer Tracheotomy care; provide overnight or weekend care where necessary; and be able to drive/transport the individual where required.

We propose that the treating doctors and therapists should be the main gate keepers to determine what each individual needs. For those with permanent disabilities, we suggest 1 annual review, by the treating doctor, unless there is a dramatic change in circumstances warranting an earlier review. For those with a temporary disability, we suggest perhaps more frequent reviews, as guided by the treating doctors.

Depending on the disability and the individual needs, we propose that ALL essential services recommended by the treating doctor are provided – including, but not limited to:

-Comprehensive medical care starting at the current safety net thresholds;

-All recommended therapies including, but not limited to:

Occupational therapy
Physical therapy
Hydrotherapy
Speech therapy
Vision therapy
ABA therapy
Psychological treatment

-All recommended equipment be paid in full and thereby accessible by all those that need it and as soon as they need it, without wait lists that are some times 6-12 months long, if not longer. We also propose expanding the list of those items that fall under the scheme – including all orthotic equipment, etc. We propose this cover all the equipment rather than looking to private health insurers first, who's policies vary wildly, and most who don't fund the entire amounts. The equipment could remain the property of NDIS and operate similarly to the current Victorian Aids and Equipment Program where equipment that is no longer needed, is then returned to the system - but it would be different in that the ***full and realistic cost*** of the equipment would be funded ***when actually needed***;

-All doctor/therapist recommended medical supplies be provided automatically and free of charge on a regular basis – i.e., eternal nutrition/formula, continence aids, catheters, syringes, feeding tubes, suctioning equipment, oxygen and associated equipment, etc.

-Integration aides be hired by and trained by NDIS and provided for the actual amount of hours/day a special needs child requires, in whatever school setting that child attends – whether it is a public school, a private school, an independent school or even a special needs school; these Integration Aides could then be matched with an individual's level of need. Therefore if a child needed an Aide who could use sign language, then one would be available; if a child needed an Aide who could peg feed, one would be available; if a child needed an Aide who could attend a trache or provide oxygen, one would be available. Currently Aides are not fully funded across the board and to the best we can ascertain, it is left to each individual school setting to hire their own Aides. From what we have ascertained, these Aides are often high school students who have never had any training in the teaching field whatsoever, let alone specialist training, as they are paid only a very minimal salary.

-A substantial increase in the home renovation grant – if suitable accommodation is not available for those that are physically challenged, the once-off home renovation grant that is currently $4,000 + $400 GST, should be dramatically increased (ten-fold would not be unrealistic) to cover a more realistic amount that a family trying to accommodate a disabled relative is more likely to incur, and we suggest expanding this to extensions, where necessary, as well.

-All medications prescribed by the treating physicians be covered in full – including private prescriptions and compounded medicines, etc.;

-All attendant care and/or nursing care prescribed by the treating physician as necessary to maintaining each disabled person's safety, well being and activities of daily living, even if it is 24hrs a day for 7 days a week. Currently almost all care provided to a person in need falls well short of what they truly need to be able to handle the activities of daily living;

-Long term, regular counseling for those who are disabled, their carers, their siblings and their families, as needed. [3]

-Appropriate accommodation for those who are disabled irregardless of their age.

-Regular, predictable and reliable respite for carers, with known and fully trained carers as much as possible.

## **Funding**

Hopefully such a scheme would help consolidate many current federal, state, local, private and non-profit systems for the disabled into one, therefore saving on bureaucratic

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[3] We have been informed of some agencies that will kindly offer i.e. 6 sessions of counseling either free or at a reduced rate. However, many times these situations require LONG-TERM, ONGOING counseling, and 6 sessions is often hardly enough time to even acquaint a therapist with the whole situation! As such, it could be seen as a useless benefit in many cases.

costs and overlap. Hopefully such a system would ease the current and humongous administrative, bureaucratic, hands-on care and financial burdens on families. This in turn would enable the current primary caregivers to perhaps be able to sustain some sort of regular outside employment to help contribute back to society and help reduce family and carer financial breakdown, depression and mental breakdown.

There probably would be the requirement of an additional tax on all individuals in Australia, very similar to the current TAC levy collected with car registration.

## Organizing and Implementing a New Disability Policy

We suggest streamlining many current disability providers and regulators into one. Therefore we suggest tapping in to all of the current expertise that is already in the field by recruiting employees from all of the current providers who already have a wealth of knowledge and experience in the field.

If a uniform NDIS can be implemented with one uniform, national policy, with one nationally agreed on set of definitions, then everyone involved would need to be educated as to that one policy.

We suggest streamlining the care organizations….while agencies that wished to remain private with private clients could do so….perhaps all of the different non-profit organizations could run under the auspices of the NDIS, and those private agencies wishing to join could do so as well (again, all operating with the same rules and regulations).