Response to Draft Report

Prepared for: **The Productivity Commission**
Disability Care and Support
DRAFT REPORT

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My Perspective:
As the parent of an 8 yo son with severe, multiple disabilities (physical & vision) I provide feedback on the specific request for comment on how to handle the carer payments etc in conjunction with an NDIS.

Response to Draft Report

Specific item from the Draft Report

> *Other payments sometimes classified as income support — Carer Payment, Carer Supplement, Carer Allowance, Mobility Allowance, and the Child Disability Assistance Payment — are really payments for support of people with a disability, since they encourage the provision of informal care or address people's mobility needs. These payments apply to a broader population than that covered by the NDIS (particularly care for the aged). One option would be to add the value of any relevant payments to the individual support packages of people with a disability who qualify for funded supports under the NDIS. (People outside the NDIS would continue with the current arrangements.) The person with a disability or their guardian would manage the funds. That way, people would have the maximum flexibility and sometimes people with a disability might decide to choose alternative carer options. However, this is a complex area, and the Commission seeks feedback about this option. Either way, NDIS assessments should take account of any of these payments — with information sharing with Centrelink.*

Feedback

Many families of children who, based on their level of disability, qualify for the Carer Payment do not receive this supplement based on the fact it is means tested with an income cut off at $63,000 for a combined family income.

The means testing for the most severely disabled children needs to be removed or lifted to $150,000 to give families the ability to meet just some of the unmet need at least until such time as the NDIS is established.

Once established then I believe the Commission's suggestion to incorporate payments into the NDIS individual support packages is absolutely the way to go. We need to remove the connotation of "carers" needing to be paid supplements and focus on supporting the person with the disability - no matter their age. Any continuation of the "carer" word in any supplements only dilutes the goals and intent of the NDIS and trains families from an early age they are carers - they aren't... they are parents.

If the needs of the person with the disability are met then the needs of the carer will be met by default - we don't need anything extra or special.

From our experience as a family in regional Australia our son's needs are not being met by the Service Providers meant to provide assistance in meeting the seating, mobility, technology and personal care aspects of his life.

We are constantly held 'hostage' by these organisations having to languish on waiting lists for services for even the basics such as wheelchairs, seating systems, seating reviews due to growth, toilet/commode requirements, communication devices and/or basic communication strategies... sometimes up to 2-3 years for services.

Often the service is poor quality and still fails to meet the needs of the person with the disability and you have no way of choosing a better or different service because Government funding requirements state you must use organisations such as the Cerebral Palsy Alliance (formerly The Spastic Centre of NSW) provide all requests for equipment or prescriptions.

Even the Department of Education can't access their funding without referrals or recommendations from the relevant therapists from local services - this means even though there are "pots of money" available we can't access them because we sit on waiting lists waiting for services for basic referrals.

Our son is 8 years old. He has been provided one seating system via the then PADP and support from the Occupational Therapist from the then Spastic Centre. He can no longer sit in the seating system and despite hours and hours by us trying to find solutions he still remains on a waiting list for a seating review.

We have had to purchase our own equipment due to the urgency of his needs - he is the most severe category of physical disability for Cerebral Palsy and has a significant vision impairment.

In the last 1-2 years we have had to purchase a number of 'big ticket items' outlined in the table below.

Where possible we have purchased either second hand items or items from overseas. We are more than happy to have this type of control and ownership over our son's future and life, we just need assistance in being able to afford such items. We are even more happy to save the Government money (notice over $20K saving to Government) as it means more for everyone - but we are really struggling to meet the needs of our son's equipment with no way to be reimbursed for these purchases.

REQ. ITEM PURCHASED	COST TO OUR FAMILY	SAVING TO GOVERNMENT
Soft Sitter positioning Seat (on sale)	$1,300	$2,000
Communication Device	$2,500	$15,000
Classroom high/low chair	$1,000	$5,000
Computer for school	$1,000	nil, DET now provided one
Everyday lightweight wheelchair	$400	$3,000
Standing frame	$2,500	$4,000
Bath seat	$800	$2,400
Multiple switches for access	$700	$700
TOTALS	**$10,200**	**$32,100**

If we'd been able to access the Carer Payment it would have covered off the price of all these items to us and we wouldn't have a concern about making ends meet. There is a huge saving to the Government if they don't have to supply these items to us because we will 'shop for the best deal' rather than the Government being take for a ride by suppliers.

We are still needing to find some money to purchase a safe car seat, hoisting for in the home (so we can receive some respite options not currently possible without these items), seating review, powered mobility if available, home modifications, software purchases, vision support equipment for home, hoisting harnesses, changing facilities for in the home (again for respite), portable changing options for out & about to allow attendance at school excursions etc, toileting commode for in the home and bidet option for personal care, new communication switch/access options, next stage in communication device, custom built switching box for our son's specific access needs.

Based on the severity of our son's disability it isn't possible for both of us to work full time - there isn't after school care options readily available - there isn't even a guarantee he can attend school every day if the school can't find aide support for him to attend and he is then asked to stay home. We don't earn big incomes in an effort to find a balance between meeting our son's needs and 'getting by'.

Our approach though is sound. Our son is now using his communication device to be undertaking school work at an age appropriate level (if not above), in a mainstream class. This is a child once described by NSW DET as the "most disabled child ever to be mainstreamed" and yet, through our determination to not "wait" for services he is now considered a child with a bright potential. He will always need life long support - but he now has a future with career opportunities and so much more.

He is the child least likely to succeed and yet is living a life beyond all expectations of the service providers, medical profession and Not for Profits. This is what happens when people who truly have a vested interest in their child have control over the direction of their child's life. We self funded trips interstate to get his communication on track with quality speech therapists. We just need some support to continue to provide him the best chance to meet his potential and continue on track for an independent life with appropriate supports.

Solution

Families are usually smarter and far less wasteful than the 'Not for Profits'. We know our kids lives depend on us getting it right - the Not for Profits have no such accountability. They are bound by ridiculous rules and systems and have the potential to waste money and time for all concerned. By putting the power back into the hands of the families and person with a disability we can make these Not for Profits more accountable and ideally more efficient.

Please consider lifting the income means test for the Carer Payment until such time as the NDIS comes into force. Help families such as ours - currently disadvantaged due to regional locations, poor services and lack of vision by the service providers - to truly change the future for our children with multiple, severe disabilities.

Once the NDIS is established allow families to "cash out" parts of the NDIS that don't meet their child's specific needs just as you will allow people with disabilities to do. Free us from the Not-for-Profits currently stifling many of our kids development and allow us to choose only people who will 'value add' to their lives.