

Submission

Re: Commonwealth Risk
Management Inquiry based on
Auditor-General's Report 18
(2015-16) –
Qualifying for the Disability
Support Pension

INTRODUCTION:

I am the mother of four children. Three of my sons are autistic. My two eldest have multiple disabilities and are DSP/Mobility Allowance recipients and they both live in DHHS residential accommodation (for people with severe disabilities) and have done so since 1999.

- *A, , has severe autism, severe ID, schizophrenia, severe epilepsy.*
- *B, , has profound autism, severe ID, Bipolar Disorder, Tourette's Syndrome, severe epilepsy, ADHD, is non-verbal and has a PEG for supplementary enteral nutrition.*

On September 22nd, I received a DSP Review letter for B (addressed to him) which only gave me till October 5th to comply before the DSP would be suspended.

I have several issues with the time frame for compliance, target demographic, costs incurred, transition between specialists and also DSP eligibility and process.

My submission will cover the third and fourth points listed below:

Audit objective and criteria

5. The objective of the audit was to assess DSS's and Human Services' administration of DSP eligibility processes. Four high-level criteria were examined to form an opinion against this objective:

- qualification processes—including how impairment and work capacity were determined and whether Job Capacity Assessments appropriately assessed applicants' eligibility for DSP;
- appeals processes—whether processes were effective, efficient and timely;
- reviews of recipients' continued eligibility for DSP and whether these reviews were appropriately targeted; and
- performance and assessment processes—whether as a program DSP was effectively measured, monitored and reported.

TIME FRAME FOR DSP REVIEW IS MANIFESTLY INADEQUATE:

- *The DSP review letters were sent to B (at my address) but not to me as the Nominated Person for Centrelink.*
- *The DSP review letter arrived ONE week late.*
- *It said that I had 21 days which I didn't. I only had two weeks. Every person that I have spoken to, who has received a review, has had them arrive late.*
- *I have heard of cases where NO letters arrive and the first thing that alerted the disabled person to the review was that their DSP was suspended without notice.*

- *The time allowed for the process of obtaining medical reports should be **at least two months** from **receipt** of the review letter.*
- *Why should the time frame be extended? Because of the difficulty in getting any appointments to specialists.....often the waiting time for appointments is two months. **I was unable to get any reports from B's neurologist, GP, psychiatrist, without attending their rooms PERSONALLY.***

TARGET DEMOGRAPHIC:

- *The DSP review has been sent to DSP recipients who are SO disabled that they are in state government care, like my sons. Why?*
- *I have regularly visited Centrelink with DHHS Resident Financial Plans and State Trustee CERS invoices (which they have photocopied) showing rent deductions for their residential care!*
- *Both of my sons were in care **before** they turned 16 and applied for the DSP so it was WELL ESTABLISHED that they were requiring high levels of care.*
- *Both sons went through Special School/Special Developmental Schools...and were assessed for the Futures Program by the Federal Government when they turned 18.*
- *From the time they were first diagnosed with autism/suspected autism (approximately 3 years of age), their specialist, a Professor of Child Developmental Psychiatry regularly filled in medical review forms so that I could receive the Child Disability Allowance.*
- *They are both in receipt of the Mobility Allowance, which entails their ATSS (day placement) sending in letters confirming their attendance hours in specific programs for the severely disabled and also a brief description of necessary life skills offered in these.*
- *All of my three sons are on the State Register for DHHS DAS, all having been assessed using the Vineland, by a clinical psychologist...and as such, are deemed significantly disabled to qualify to be on the register.*
- *With regard to ALL of the above points WHY are these reviews sent to severely disabled people who have manifest conditions and whose Centrelink history is well recorded and easily substantiated by simple verification of their situation with DHHS?*
- *Why have these DSP reviews been sent out in contravention to their own risk assessments on the Centrelink website:
<https://www.humanservices.gov.au/corporate/budget/budget-2016-17/disability-and-carers/national-disability-insurance-scheme-savings-fund-medical-risk-based-review-current-dsp>*

Reviews will include certain DSP customers who are most at risk of not meeting eligibility criteria. The Department will use a risk profiling based approach to select people for review. Reviews will apply the current DSP qualification criteria using the January 2012 revised Impairment Tables.

With regard to this, and considering all of the above facts relating to my second son, B, WHY WAS HE SENT A REVIEW?

Centrelink should be triaging the DSP recipients and following their own risk assessment protocol. When both of my sons were granted the DSP, I was told that they would never be reviewed for the rest of their lives.

COSTS INCURRED:

- *The visit to the neurologist by just myself, (as the only time I could book within the two weeks till the deadline) was when B was in transit on the house bus from his ATSS – cost \$130 non-Medicare rebatable as the patient was not present.*
- *Both boys could not attend the GP so, unless I went as a patient in my own right, \$70 each.*
- *The two other specialist appointments – one neurologist and two psychiatry appointments where each boy could attend were regular ones where the specialists spent much time writing a letter and printing it during the visit. Cost to Medicare would be approximately \$550 plus out of pocket GAP costs of around \$60.*
- *Time. I drove, well out of my area, to a GP and two specialists on three separate days during the second week of the school holidays (so did NO activities with my third autistic son who stayed at home)...then one night the next week to the gastroenterologist. Have visited two specialists and a GP for my eldest son since...as I am expecting a DSP review for him as well.*
- *Petrol. I have easily gone through a tank of petrol with seven trips to doctors to get individual reports at short notice.*

TRANSITION OF SPECIALISTS:

- *Both conversations that I had with Centrelink made it clear that I had to get all of the following points (refer to this portion of the review letter) complied with.*
- *The trouble was that B had transitioned to new specialists and that medical histories had not come over.*
- *This is COMMON with disabled people of adulthood who have left their paediatric specialists and clinics and transitioned to adult ones. Files do not go with them, especially from public outpatient clinics.*

Diagnosis

- The formal diagnosis of the medical conditions that impact your ability to function.
- When each medical condition was diagnosed.
- The name, qualification and contact details of the medical professional who made the diagnosis.

Treatment and care

- The type of treatment that has been undertaken in the past.
- The current treatment(s) you are undertaking.
- Planned or future treatment, including whether you are on a waiting list.
- If you require specific care because of your condition, including nursing home level or palliative care.

Symptoms and functional impact

- When the symptoms of each medical condition started (date of onset).
- Current symptoms of your conditions (persisting despite treatment, aids, equipment or assistive technology).
- The severity, frequency and duration of your symptoms.
- How your conditions and treatment impact on your ability to function in day-to-day life including at work.

Prognosis

- The length of time the condition is likely to impact your ability to function.
- Whether the condition is likely to improve, remain the same or get progressively worse.
- Whether your medical condition is likely to significantly affect your life expectancy.

- *Specialists, that have treated a disabled person IN THEIR THIRTIES and OLDER, often are retired or deceased.*
- *Centrelink wanted EVERY one of B's diagnoses, which were made by his Professor of Child Developmental Psychiatry, itemised with the date, onset of symptoms, etc and relevant tests. At the time of the review letter, we were with a new dual disability psychiatrist who had only seen B ONCE a few weeks previously and had no referral letter or medical history. It was impossible to obtain anything from his professor who was now semi-retired. (I did request this.)*
- *He had attended the _____ Clinic as an outpatient and had just started seeing a private neurologist in March this year. No notes went over.*
- *He was under an adult gastroenterologist but none of his notes from the Royal Children's Hospital were available.*
- *In the absence of these, the second Centrelink person told me to produce his original diagnosis letters and copy them. **I went into the storage space of my husband's shed roof and retrieved ancient autism diagnosis reports from 1988/89/90!!! I thought that I had thrown them out! Who keeps 27 year old reports?? Ridiculous!***

DSP ELIGIBILITY AND PROCESS:

- *The INSISTENCE of a Wechsler WAIS IQ test is a bizarre request when one considers several factors.*
- *Autism is a neurobiological condition that is INDEPENDENT of an intellectual disability....often people with autism have a co-morbid ID but an ID, per se, is NOT part of the autism condition.*
- *Having a WAIS test is prohibitively expensive – current rate for this test performed by an experienced clinical psychologist is \$700.*
- *An autistic person, such as my two sons, with SEVERE CHALLENGING BEHAVIOUR common to autism, would NOT comply with the tester and would, most likely ATTACK the tester.*
- *The request for this test ignore several other factors....the ability to comply in any sense due to autism....and the WELL KNOWN triggers for a meltdown which are unfamiliar person and an unfamiliar setting.*

Specific medical evidence required for some medical conditions

We need specific medical evidence for some medical conditions. This includes:

- **ear conditions affecting hearing or balance:** the diagnosis must be supported by a report from your audiologist or ear, nose and throat specialist.
- **eye conditions affecting vision:** the diagnosis must be supported by a report from your ophthalmologist.
- **mental health conditions (such as depression, schizophrenia):** your doctor's diagnosis must be supported by a psychiatrist or clinical psychologist assessment.
- **intellectual impairment:** we need an assessment of intellectual function and assessment of adaptive behaviour from your psychologist, or a report from your special school which includes these psychologist assessments. Evidence you provide must include information supported by a psychologist about your IQ score, or your ability to undergo IQ testing.

For more information, go to humanservices.gov.au/dsp or call us on 132 717.

- *Autism, especially severe autism, should be in a SEPARATE category as there is NOT one criteria in the manifest conditions that accommodates this disability. (see below)*

4 Manifest grants of the DSP are made without further assessment in the following limited circumstances: a terminal illness (life expectancy of less than two years with significantly reduced work capacity during this period); permanent blindness (meets the test for permanent blindness for social security purposes); an intellectual disability where medical evidence clearly indicates an IQ of less than 70; an assessment indicating that they require nursing home level care; category 4 HIV/AIDS; or in receipt of a Department of Veterans' Affairs disability pension at special rate (totally and permanently incapacitated). Two lists of conditions have been available since 1 July 2010, to help decision makers determine manifest eligibility for DSP on the grounds of terminal illness, nursing home level care requirements, and/or intellectual disability.

- *Also, many young people with disabilities MIGHT have had a Wechsler WPPSI or a WISC for an SNQ (Special Needs Questionnaire) done at preschool age to assess eligibility for mainstream schooling/integration aide allocation/eligibility for Special School of IQ 55-70 or an SDS up to 55.*
- *Per the second Centrelink call, after the review letter arrived, I was asked to retrieve old Wechsler results and Centrelink insisted that he MUST have had one at some time....not true.*
- *My eldest son A had a WISC done and my youngest C has had a WPPSI but the second son, B, has NEVER been given ANY IQ test, nor required to have one. He automatically went into an SDS after his initial school....because he had a PEG tube and required school staff to feed him. This could only be done at an SDS. Also he was in nappies till the age of 11 years.*
- *I refused consent for B to have a test, with a quote from a previous report that "B has a tendency to violent outbursts that are managed by behavioural strategies and that he will kick, slap and bite quite unpredictably." I am NOT going to put my son in a needlessly stressful situation. The older son has paranoid schizophrenia, is 6' tall and wears size 2XL clothes and it could be dangerous.*
- *It is of note that of the approx. 2500 disabled residents in DHHS care, there are approx. 2000 of these under trustee companies without family members to do this running around. What happens then??*

OUTCOME:

- *Regarding the outcome of B's review....*
- *After this, on the same Thursday, I received a call from Centrelink management saying that B's DSP review had been approved on the basis of one faxed letter from his gastroenterologist.*

- *I stated that the gastroenterologist was in charge only of his PEG, which was a minor medical issue and not one of his other many disabilities for which he had two specialists.*
- *The gastroenterologist only mentioned that B was in care and noted some of his disability issues in a sentence but he is NOT the treating specialist for these. He has NONE of the reports relevant to epilepsy, autism, bipolar disorder.*
- *I also said that Centrelink had NONE of the other three reports which were in my possession.*
- *I told her that I was planning to take all of the four reports to Centrelink the next day (Friday) and could I still do that? **She said that they didn't want them.***
- *By approving B's review, they have not adhered to their criteria (see attachment D)*
- *Why was B's review approved without the sighting of the reports that I was ORDERED to get?*

SPECIALIST COMMENTS:

From the neurologist's report for B:

I was approached by [REDACTED]'s mother, to provide a medical report to CentreLink as [REDACTED]'s treating neurologist. **Procuring reports at short notice is a very traumatic exercise for families in this situation and I think it is important at the outset to point this out to CentreLink. Requesting this type of correspondence regarding patients like [REDACTED] is a complete waste of time for all concerned and I have no idea what managers in Centrelink were thinking when they initiated this process.**

There is no question in my mind that he is not in a position to work and needs ongoing long-term community supports and will need to stay on a disability support pension until the day he dies.

From the neurologist's report for A:

There is no question in my mind that he is not in a position to work and needs ongoing long-term community supports and will need to stay on a disability support pension until the day he dies.

His family are fortunate in that they only have two children on a DSP as this harassment from Centrelink hopefully will now end.

RECOMMENDATIONS:

1. Centrelink *MUST* liaise with state government authorities such as DHHS DAS section and CROSS CHECK names against the state register to improve targeting
2. DSP review letters should be sent to the recipient AND the nominated person.
3. DSP review letters should arrive in a timely fashion NOT a week later.
4. The time for a DSP review to be complied with should be 8 weeks, not 21 days.
5. The condition of Autism bears NO relationship to any of the manifest criteria, especially ID below 70. It should be in a category on its own. Autism, especially severe or profound autism, manifests itself with often severe challenging behaviour, social isolation, communication difficulties (half are non-verbal – B has NO communication system whatsoever), two thirds have epilepsy.
6. Requiring dates of diagnoses, symptoms, etc from CURRENT treating specialists in the absence of archival medical history from previous treating specialists and public hospital clinics is problematic and MOST unhelpful.
7. The SHEER COST to Medicare and out-of-pocket costs to the disabled person are prohibitive and wasteful.
8. The thousands of DSP recipients under trustee management.....what happens to these totally dependent people when they, themselves, are totally unable to comply with reviews?
9. At age 16, when my two sons were granted the DSP, and also in reference to the medical report from their professor, we KNEW that they would never be able to work then....that they were already in fulltime care....that they would only be in day training centres when they finished schooling.

There is NO cure for autism.

There is NO cure for schizophrenia and bipolar disorder.

There is NO cure for epilepsy, especially life threatening, unstable epilepsy like the eldest son's.

Why is there need for these reviews NOW when we were patently told that they both would NEVER be subjected to reviews ever? The boys have not improved. In fact, their disabilities are more complex and WORSE.

Audit objective and criteria

5. The objective of the audit was to assess DSS's and Human Services' administration of DSP eligibility processes. Four high-level criteria were examined to form an opinion against this objective:

.....reviews of recipients' continued eligibility for DSP and whether these reviews were appropriately targeted;

ATTN EPIC FAIL.



Australian Government
Department of Human Services

Disability Support Pension Review Medical Evidence Requirements

Medical evidence to support your review for Disability Support Pension

You need to provide current medical evidence from your treating health professionals to support the review of your medical eligibility for Disability Support Pension. We need this information to help us understand how your medical conditions affect you, and to make sure we correctly assess your eligibility.

We are not responsible for obtaining this information on your behalf. However, we may contact your treating health professionals to confirm or clarify information you provide about your medical conditions.

Information we need to assess your eligibility

You must provide current medical evidence about each of your medical conditions that impact your ability to work. These requirements are explained in more detail below.

You need to provide suitable medical evidence within 21 days of being notified of this review or as soon as possible afterwards. If you do not provide evidence within 21 days your payments may be stopped.

Please tell us if you cannot provide evidence within that time, or if you are having difficulty obtaining current medical evidence.

If you do not provide sufficient current medical evidence we may take longer to finalise your review, or payments may be stopped.

What is medical evidence?

Medical evidence includes documents written by a registered medical practitioner (such as your treating doctor) and other registered health or allied health professionals. This evidence should support information about the functional impacts and level of impairment that result from your condition.

Statements about your condition written by you or your nominee are taken into account, but are not considered medical evidence. This applies to information provided by a person who is not a registered health professional, such as a teacher.

Examples of medical evidence you should provide:

- medical history reports/print outs
- specialist medical reports, including outcomes of specialist referrals by your treating doctor
- allied health professional reports, such as physiotherapy or audiology reports
- psychologist reports, including IQ testing reports
- medical imaging reports
- compensation and rehabilitation reports
- physical examination reports
- hospital/outpatient records or discharge summaries including operations you have had.

Medical evidence should be as current as possible. Older evidence (such as reports or records more than 2 years old) will generally be considered less relevant. Please talk to your treating health professional if you are not sure whether the medical evidence you have reflects your current circumstances.

Information we need about your medical conditions

We need current information about the diagnosis, treatment, symptoms, functional impact and prognosis of each of the medical condition(s) that impact your ability to work. This is explained in more detail below:

SA474.1607

Diagnosis

- The formal diagnosis of the medical conditions that impact your ability to function.
- When each medical condition was diagnosed.
- The name, qualification and contact details of the medical professional who made the diagnosis.

Treatment and care

- The type of treatment that has been undertaken in the past.
- The current treatment(s) you are undertaking.
- Planned or future treatment, including whether you are on a waiting list.
- If you require specific care because of your condition, including nursing home level or palliative care.

Symptoms and functional impact

- When the symptoms of each medical condition started (date of onset).
- Current symptoms of your conditions (persisting despite treatment, aids, equipment or assistive technology).
- The severity, frequency and duration of your symptoms.
- How your conditions and treatment impact on your ability to function in day-to-day life including at work.

Prognosis

- The length of time the condition is likely to impact your ability to function.
- Whether the condition is likely to improve, remain the same or get progressively worse.
- Whether your medical condition is likely to significantly affect your life expectancy.

Specific medical evidence required for some medical conditions

We need specific medical evidence for some medical conditions. This includes:

- **ear conditions affecting hearing or balance:** the diagnosis must be supported by a report from your audiologist or ear, nose and throat specialist.
- **eye conditions affecting vision:** the diagnosis must be supported by a report from your ophthalmologist.
- **mental health conditions (such as depression, schizophrenia):** your doctor's diagnosis must be supported by a psychiatrist or clinical psychologist assessment.
- **intellectual impairment:** we need an assessment of intellectual function and assessment of adaptive behaviour from your psychologist, or a report from your special school which includes these psychologist assessments. Evidence you provide must include information supported by a psychologist about your IQ score, or your ability to undergo IQ testing.

For more information, go to humanservices.gov.au/dsp or call us on 132 717.