Fewkes, Nathan (REPS)

From:

Subject: FW: Submission: Inquiry into Qualifying for the Disability Support Pension

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SUMBISSION

Commonwealth Risk Management Inquiry based on Auditor-General's report 18 (2015-16)

Inquiry into Qualifying for the Disability Support Pension

I am writing a submission to this Inquiry as the mother of two children with a rare disabling medical condition

Over the last few years I have had to assist my daughters in applying to CentreLink for Disability Support Pension and Carers Allowance and helped others who also have Ehlers-Danlos Syndrome. As a teacher of 30 years' experience, I have seen first-hand how hard it is for young people with a disability.

Firstly let me say that people with a Disability have so many additional problems and expenses in their life that others don't even think about, including: medications, appliances, braces, life aides, mobility devices, cranes, modified private vehicle (including rego, insurance and maintenance) if unable to use public transport, modified clothing, air-conditioning and heating are a necessity not a luxury for many, modified housing, specific bedding, assistance dogs and their maintenance, specialist appointments, private health cover (essential for fast efficient treatment), finding and paying for carers, travelling the country trying to find specialists who understand their condition, moving to another city to access specialist medical care, finding and keeping friends and partners, family stress, money worries, living below the poverty line, unable to work, unable to find suitable work, intolerant employers, discrimination, access to education, anxiety, depression, feeling like a burden on their family, guilt, suicide.

For these reasons, I know how much our family appreciates every little bit of help we get from the government and we say thank-you from the bottom of our hearts!

But no matter how hard we to try to stay positive and approach life with a 'Can Do' attitude, let me tell you how many times we get knocked down and have to get up again and fight on. Sadly, young children with a Disability learn that life is tough and people can be cruel.

Government red-tape, paper-work, tough policies, unrealistic expectations and disbelief are making life even harder for those with a Disability. We have had to fight for every little bit of help we have received and had to wait months for approvals and appeals. Life is already so tough for them!

We have come across many problems and issues that face people with Disability in trying to apply for the Disability Support Pension and deal with reviews.

Problem

The government is purposefully trying to reduce the number of people on DSP to save money, so the process and the forms are purposefully made to be difficult to deter people from applying. But people with genuine disability find the whole process and the incumbent deterrents extremely stressful, costly and problematic.

If the government genuinely wants to save money, then streamline the process and save money on waste and repeated assessments.

Problem

3 hour waits on the phone answered by staff who do not even work in the Disabilities area and are not knowledgeable in disability policies and forms. This means being transferred again and another 3 hour wait on the phone. The callback system does not work any more. Sometimes every operator you talk to gives you a different answer.

FORMS

Problem

Many doctors have difficulties completing the application forms due to lack of understanding of the questions and medical terms – even doctors are sometimes unsure which categories symptoms belong to. For example some doctors do not realise that Dysautonomia symptoms should be included under the neurological category.

Problem

Even Doctors are sometimes not sure who can complete the forms related to DSP (such as Medical Appliances Subsidy) so patients get the run around.

Problem

Many of the symptoms of **Rare Diseases** are not covered in the questions on the application form. For example, the Application Form lists Osteogenesis Imperfecta, but not Ehlers-Danlos Syndrome, yet both are debilitating Connective Tissue Disorders, just that EDS is much rarer.

Problem

Rare diseases are frequently misdiagnosed by GP's and even specialists, due to lack of knowledge and understanding, so medical reports can be conflicting. People with Ehlers-Danlos Syndrome usually wait more than 10 years before getting a correct diagnosis.

Problem

If you are seen by a government doctor, what guarantees will the public have that the doctor is familiar with their Rare Disease? On Average EDS patients usually need to see more than 10 different specialists before they get an accurate diagnosis. So how is one doctor going to make an accurate decision about a Rare Disease.

Problem

The Form does not adequately cover intermittent but recurring problems, such as frequent recurring dislocations due to permanently faulty collagen. My daughter dislocated her shoulder 9 times in one week. However, one assessor decided this was not a permanent condition because the dislocations were intermittent. Many medical conditions can have flare-ups that are very disabling for the patient and a severe interruption to their lives.

We have had assessors report that the neurological symptoms of Ehlers-Danlos Syndrome is not a permanent condition because they are intermittent.

Problem

The DSP criteria do not take into account the fact that people with **Rare Diseases** can have many complex symptoms occurring simultaneously, which individually may seem insignificant, but together they creating a very disabling condition.

Patients with Rare Diseases often have many symptoms going on, and spend years going from doctor to doctor trying to find answers, and remain without a definite diagnosis, because no one has been able to put all the symptoms together under one umbrella. This is certainly true for Ehlers-Danlos Syndrome.

Problem

Some symptoms make it impossible to work; such as nausea, pain, fatigue, Dysautonomia, migraines, gastroparesis and mast cell activation syndrome. But these are not covered on the DSP criteria. Combine several of these symptoms together and the person becomes very disabled, but not in a way that is easily visible or obvious. This is the case with Ehlers-Danlos Syndrome and many other rare conditions.

Problem

Many statements on the form are misleading and do not collect the right information to make a proper informed accurate decision.

Problem

Many statements require further explanation for both doctors and patients, which I was only able to get after a 3 hour wait on the phone to talk to the right person who could explain properly.

Problem

Permanent genetic conditions should not require frequent reviews and re-assessments as these conditions do not suddenly disappear. This is especially true for conditions that have no known cure or treatment, but require constant management.

Problem

There is confusion between treatment and management. Treatment controls the symptoms, such as insulin is used to control diabetes. Management just helps to alleviate the symptoms temporarily but they do not disappear. Some diseases have no treatment, but do need to be managed regularly, requiring frequent visits to many specialists.

Problem

Patients often have great difficulties answering the questions on the forms, and often have cognitive or neurological conditions to deal with as well. To get help from CentreLink means a long wait on the phone.

Problem

I have to advise people to answer the questions based on their worst days (rather than being modest and answering based on their best days) to reflect reality.

Problem

Teenagers especially hate being honest about their symptoms as they are desperately seeking their independence and don't always want to admit how severe their symptoms are.

They also realise that by admitting how severe their symptoms are, may prevent them from being accepted into places of study, or finding a party time job.

ASSESSMENTS

Problem

Assessments are not always done by doctors.

Problem

Assessment teams are not up to date with knowledge about rare conditions.

Problem

Applicants may look OK on the outside, but may be a genetic mess on inside, leading assessors to the wrong conclusion. Many applicants are too sick to attend assessment appointments on a flare-up day and can only manage to attend on a good day, again giving the assessor the wrong impression.

Problem

Applicants are asked to explain how the condition affects their daily life. Even after writing pages and pages of details, it seems to be ignored or treated with disbelief.

Problem

Frequent assessments are wasting doctors' (and patients) time; there are long wait lists to see doctors in the public system so it is difficult to meet deadlines for submitting forms; going to private specialists is too costly for most;

Problem

Unnecessary frequent reviews are wasting precious tax payers money.

Problem

Reviews take weeks to finalise.

Problem

Every government department and provider wants to do their own assessment resulting in repeated unnecessary assessments and a waste of tax payers' money. One assessment should be able to cover all government departments' and providers' requirements.

Problem

Inconsistency: CentreLink and Disability Services both assessed my daughter as being Disabled, but Disability Services said her genetic condition was not permanent!!!!!!

Problem

Youth Disability Allowance does not carry on to Disability Support Pension and requires another assessment be done!

Problem

How many doctor's reports are needed to prove disability?

You only need to look at the size of my daughter's hospital files to see she is seriously ill and disabled.

Problem

Recurring, repeated illness, surgeries and hospitalisation also makes you disabled (ie unable to work, study, volunteer, look for work, socialise and participate in family life) even if you are still waiting for a diagnosis and a cause for your illness. EDS patients can wait longer than 10 years for an accurate diagnosis.

Problem

Many of the medical descriptions about abilities of children are for very young children and do not cover older children or adolescents attending school.

Problem

No mention is made of disruption to schooling.

Problem

One assessor denied my daughter support from Disability Services because she can "just keep going back to hospital for treatment". This is a ridiculous statement because her condition is a permanent genetic syndrome and has no cure or treatment. She has been into hospital over 70 times and had 8 operations and she is only 21 years old. This has been totally disruptive to her ability to work, study, volunteer, look for work, socialise and participate in family life.

Problem

Requirements to prove disability are far more demanding, difficult and expensive than requirements to prove you are legitimately wanting to/prepared to/looking for work.

Many people accessing unemployment benefits who can work, but simply do not want to work.

It's amazing how many people with disability, who can't work full time, actually **want** to be able to work. When you can't do something it often inspires you to want to do that thing. But some people just can't and never will be able to!

Problem

The people who are suffering the most are being tested the most.

How many times do we need to prove our identity, which requires another trip in to CentreLink, as no one likes posting their original documents in the mail.

Problem

Disabled people already spend so much of their limited money on health care and they can't afford unnecessary repeat visits to doctors just to fill out more forms.

Problem

Even if they want to, Disabled people often can't work (even volunteering) due to their symptoms.

If they can work a few hours, they usually can't find work suitable to their specific needs and symptoms and understanding employers who will put up with unreliable attendance due to recurring illness. Discrimination is still rife in our community.

If you have tried working a part time job, to see what's suitable or what you can cope with, you will be judged as able to work and therefore NOT disabled and not eleigible for the DSP. Even if you had to give up that job because you couldn't cope, that is not recognised by CentreLink. This is why many disabled people will not even attempt to try a part time job.

When a person is going through a good patch, they may be able to do more work, but if they are having a flare-up they may not be able to work at all. Every medical condition and every patient is unique! Please recognise that most people applying for DSP are not able to work at all, hence the need to apply for DSP as their only source of income.

Problem

Disabled people can't afford to spend money on travel or petrol if they can't get Mobility Allowance because the requirements are too tough and unrealistic. If you can't study, look for work, work or volunteer then you can't get mobility allowance. But you still need to go the doctors, hospital, specialists, CentreLink, shopping, chemists etc.

Solutions

If the government genuinely wants to save money, then **streamline** the DSP process and save money by cutting out wasteful procedures and repeated assessments.

Provide more timely and efficient phone help for DSP applicants with knowledgeable and specialised personnel.

Properly and unambiguously explain the phrase "treated and stable". There is not treatment for life-long, permanent genetic conditions. Often these conditions are never stable.

The DSP form needs to include **more criteria and symptoms** to cover Rare Diseases, such as nausea, fatigue, pain, migraines, Dysautonomia, gastroparesis, POTS, Mast Cell Activation Syndrome.

Descriptions of children's abilities need to be broader to cover school age children and adolescents.

The DSP form needs to recognise the many **new diseases of the 21st century** such as Fibromyalgia, ME/CFS, auto-immune diseases.

The DSP form needs to be **better explained** for the sake of applicants and doctors.

A separate **explanation sheet** could be provided to explain each question in detail and give clear unambiguous examples.

Take more notice of information about how the disability affects the applicant's **daily life**. The examples on the DSP form are too limited. Expand this section of the form.

The DSP form must make it very clear **WHO** is able to complete all the associated forms.

An assessment should be completed by a **team** of **doctors**. Not psychologists or other health professionals!

An assessment should consider many **different reports from different specialists**, not rely on the decision of one doctor, especially in the case of Rare Diseases.

Recognise conditions that are clearly **life-long, permanent, genetic conditions** that will not 'disappear'.

In the case of life-long, permanents conditions, assessments (and proof of identity) should be deemed to last at least **5-10 years** before re-assessment is required (unless circumstances change, such as a cure is developed).

Once an Assessment is complete it should be **recognised** by any government or private agency across Australia, just as a death certificate is accepted by everyone. This will save money for the government by not having every agency repeat assessments.

Recognise the added burdens and costs that people with Disability have and make sure that people on DSP automatically be asked and **allocated other supports in the assessment** (such as mobility, electrical appliances, telephone) as each of these relies on another form and another trip to the doctor……wasting the doctor's time and the patient's money. Money that disabled people don't have! Even a simple trip to the doctors is often difficult for many with disabilities.

Allow people on DSP to **try part-time work** without judgement or cut backs to their Pension.

Unless they miraculous develop a cure for life-long genetic conditions, **do not cut additional supports**, such as mobility allowance, because of a **temporary change in circumstances**, such as temporary inability to study or volunteer. This just means reapplying again and again every time circumstances change. Those with complex conditions **will** have their circumstances change regularly, beyond their control. By allowing this flexibility, you will be helping and encouraging people to find something they can do to contribute and maintain self-esteem.

Recognise that because someone can't work, doesn't mean they can't contribute to society and their family.

Make the requirements for Youth Allowance/unemployment just as tough as the DSP requirements, so money can be saved in this area and put towards people with genuine disability.

I wish she was as good on the inside as she looks on the outside!!! People often comment "You don't look sick!!!" but she often has to use a wheelchair when her dislocations, fatigue and pain are bad.

Thank you for taking the time to read my submission.

I hope that identifying these problems will help solve them and make a better life for people with Disability.

Sincerely

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