Like so many others, I have recounted my story hundreds of times to countless Support Groups, Advocacy Services and Official Bodies and have personally campaigned and lobbied for improvements, without any real effect or change. I sincerely hope that things will be different this time.

I am the parent of an Autistic child, and as such, my submission is specifically related to Autism, but the Principles apply to all those with a congenital disability or an acquired, life-long disability, and may be extended to those with short term disability for the duration of their disability.

SUBMISSION

In relation to disability, the list of 'areas for improvement' is endless. However, unless and until these **Basic Principles** are applied to each and every area of Policy, Legislation, Funding, Action and Attitude, disabled people will continue to be unfairly treated, discriminated against and led along in the merry dance of bureaucracy. We should be striving towards a model similar to the excellent one they have in the United Kingdom.

BASIC PRINCIPLES

EVERY DISABLED PERSON IS ELIGIBLE

Every disabled person has a disadvantage greater than a non-disabled person. To satisfy Basic Human Rights, **all** disabled people must be eligible for help and Support Services so that they may function in society, as much as is possible, in the same way as a non-disabled person.
Currently, some disabled people are eligible for help and some are not.

AUTOMATIC ENTITLEMENT

Every disabled person, regardless of the nature or severity of their disability, deserves and should have 'automatic entitlement' to available services, according to their needs. This is especially true for those born with a disability.
Currently, some disabled people are entitled to services and some are not.

DIAGNOSIS EQUALS PROOF

A proper **diagnosis** by an accepted Professional **is proof** that that the person has the disability for which they have been diagnosed. It is humiliating, expensive, degrading and, above all, unnecessary to force a disabled person to keep 'proving' that they are disabled in order to receive services. This is especially true for those who were born with their disability.

ONE RULE FOR ALL

The disparity between the level of help and services provided to different people with

the same disability is outrageous and incomprehensible. If **one person** moderately affected by Autism Spectrum Disorder receives $9,000 per year, then **all people** moderately affected by Autism Spectrum Disorder should receive $9000 per year. This rule must apply for all disabilities at all levels in order to eliminate preferential treatment, confusion, discrimination and neglect.
Currently, one person may receive tens of thousands of dollars in funding whilst another with the same condition gets nothing.

TRANSPARANCY - CLARITY - SIMPLICITY - HONESTY

Facts and figures need to be made publicly and easily accessible. Forms need to be simplified. People need to know, **before they apply** for help, **exactly how much they will receive** and **how long it will take.**
Currently, any disabled person (or their carer), trying to obtain any Government Service, has no idea what they are entitled to, how much they will receive or how long it will take. They must wade through a mountain of complex, misleading information and incomprehensible paperwork,...... they must follow humiliating, time-consuming, expensive and traumatic procedures and processes......often to end up with nothing after all their efforts....... and not even sure of what they are fighting for because,..... comprehensive information on all the facts and figures are not available from any source.

LOCAL COUNCIL ACCESS AND SUPPORT - RUN NATIONALLY

Every Local Council should be responsible for Disability Services in their own area, but this need to be **governed centrally** so that the **same rules apply Nationally**. Every Local Council needs to make their Services easily accessible with readily available sources of help, support, information and advice. (In remote areas, disabled people should be allowed and funded to access services from another area when services are not available in their own area.)
Currently, Local Councils are unapproachable, uninformative and unhelpful, and they have the freedom to do exactly as they please. There is no central control over the services they provide or the decisions they make.

ACCOUNTABILITY

Local Councils and authorities need to be held accountable for poor quality services. There needs to be an **Independent Body** to handle complaints of discrimination, neglect, dishonesty and incompetence and it needs to be free and permanently available.
Currently, disabled people suffer tremendous difficulty and/or expense accessing any service which is able to deal with their justified complaints effectively.

CATEGORISE - PRIORITISE - ALLOCATE - PUBLICISE

1. **Categorise** all the different types of funding, all the different types of disabilities according to severity and subsequent support needs, and all the areas in which disability funding is spent.

2. **Prioritise** which areas are most needy. This should be done according to the severity of the disability and subsequent supports needed, not according to any other consideration.
3. **Allocate** funding according to **category** and **priority**, whilst ensuring the '**one rule for all'** Principle.
4. **Publicise** this information. Disabled people need to know what services are available and how they can get it.

TRAINED, QUALIFIED, PERMANENT, FULL-TIME DISABILITY STAFF IN EVERY SCHOOL

According to statistics, every school will have at least one child with a disability, most commonly, Autism Spectrum Disorder. (The rates of this condition are increasing rapidly every year). It is essential that schools provide at least one, full-time, qualified member of staff to deal solely with 'special needs' children. Disabled children need extra help by qualified staff on a permanent basis, and if this is not supplied, then these children are having their Basic Human Rights contravened every single day.

How do we arrange all this?

STOP THE RIP -OFF BY SPECIALISTS

Taking the following steps would save hundreds of thousands of dollars in misused funds which could then be put into the correct **priority** areas.

Currently, Specialists are cashing in, big-time, at the expense of the most vulnerable members of Society, and this is enabled by current Legislation.
Medicare pays a reasonable sum to these Specialists for their Services, but the Specialists continue to charge exorbitant fees, way in excess of the Medicare rebate. This is verging on criminality and needs to be stopped.
*Disabled people are forced to use these Specialists, even when their disability does not necessitate their use because, in order to get funding for help that is truly needed, current Legislation demands a string of Specialist Reports as '**proof**' that the funding is needed.* ***The disability is proof that the funding is needed!***

There are several solutions to this problem:

1) The Government should stop demanding Specialist Reports. A diagnosis is enough.

2) The Government should put a cap on the amount Specialists are permitted to charge for their Services.

3) Create competition.
This can be done by using current Disability Funding to provide **Local Council Specialists and Teacher's Aides.** They should be paid a salary and their Services

provided, free of charge, to those who need them.
If '**Automatic Entitlement'** became Law, then Local Councils could do away with all the massive administration costs of Funding Applications and the mountain of paperwork that goes with it.
The money saved by doing this could be put into providing wages for the Local Council Specialists and Teaching Staff.
Disabled people would be happier; free Specialists would be available to them without all the paperwork and tortuous Application processes, and aid would be available in all schools.
If Local Councils provided free Specialists, then private Specialists would have to reduce their exorbitant charges in order to attract customers. The Government would no longer need to pay most of them, either through Medicare, or through subsidies given to parents. Another massive saving to be used for Real Services.

Currently, the Specialists are rubbing their hands in glee, being paid huge amounts by the Government (via Medicare) for their services..... to provide Reports which are unnecessary back to the Government (via Local Councils),...... in order for the Government to spend even more Disability Funding on Administration costs to process all these unnecessary Reports....... to ***prove*** *that disabled people, who were* ***born disabled*** *and have been* ***diagnosed as disabled*** *are* ***really disabled****........only to tell them that they won't get any funding because there is not enough money........and now, the Government, through the 'Helping Children with Autism' package is giving even more money to the Specialists for their unnecessary Reports and Services........and so, with guaranteed money available, the Specialists raise their costs even higher.......so the disabled people have to pay even more money to access Services that they don't really need.........to satisfy Legal Requirements that are impossible to satisfy........because disabled people are forced to get Reports that don't fit their disability...... and because, the Specialists want the money and none of the hard work, so they don't complete the Reports correctly......so the disabled people don't get the funding they have fought so hard for and desperately need.......because Reports are completed insufficiently or are irrelevant and there's no money left anyway.*

Even my ten year old Autistic son found this comical when I read it to him., but it is no laughing matter. The whole situation is tragic and farcical.

AN EXAMPLE:

An Autistic child may not need a Speech Therapist or an Occupational Therapist or a Psychologist to help with their problems, but they will definitely need an aide at school to help with meltdowns, aggression, anxiety, social issues, information processing issues, sensory issues and other learning difficulties.
The child is forced, by Law, to provide Specialist Reports in a whole range of areas to prove that the child meets a specified criteria to be eligible for funding. The pressure to obtain funding is so great that parents get even more Reports than necessary and

see more Specialists than they need in order to show that their child really deserves the funding that they are applying for.

So,...... we see the Specialists and get the Reports and pretend that we need them,....... because the Law states that we need them to apply for funding for an aide, ...which we never get, because the funding does not stretch that far, ...because it is wasted on administration costs to process the funding application, ...so we don't get the aide which was what we really needed,...... because half of the money was spent on obtaining the reports and paying for the specialists that weren't really needed, ...and the other half was spent on administration costs to process all the unnecessary Reports......and round and round we go.....so much waste.......so much torment....such little satisfaction!

The situation is now at the stage where the Specialists don't even believe that an autistic child will receive funding,..... but they take the money all the same, and word the Reports to the effect that 'funding is unlikely!'. ....We don't stand a chance!....

What is even more diabolical is the fact that, even if we manage to get all the reports and satisfy all the requirements,..... a teacher, who does not necessarily know the child, and who has no training in Autism,...... can put an end to a funding application immediately just by stating, in the dreaded Vineland Test, that they don't think the child actually needs it........ Why is this power given to teachers? This is wrong and needs to stop immediately. How on earth can a teacher, unqualified in Autism Spectrum Disorders possibly comment on what an autistic child might need? The Vineland Test is another measure put in place to reduce the chances of disabled people obtaining funding. **The Vineland Test is discriminatory and should be abolished.** Many schools tell parents not to bother applying because they won't get funding anyway......many others just don't want all the paperwork......how can we win against all this?

Autism and Asperger's Syndrome are for life, and **every single child** with these conditions needs extra help and support at school. This should be their **automatic Right.** If one gets help, then they all should. Who differentiates? Who decides? How is it decided? Who decides the amount? How much? So many questions.......so few answers.......it should not be this way.

The Government needs to take control and stop with the band-aid solutions. Complete and radical changes in **Legislation** are needed if anything is ever going to significantly improve.

Finally, just to make this **Fundamental Point** clear, once again:

A G.P. does not pick and choose between those illnesses he will treat and those he will not. Every person is **eligible** and **automatically entitled** to treatment, regardless of the nature or severity of their illness.

Until we extend this courtesy to our disabled people, Australia will continue to remain morally bankrupt. Legislation needs to extend this **Fundamental Right** to its most vulnerable members of society**.** Every disabled person must be made **eligible** and **automatically entitled** to help and Support Services, regardless of the nature or severity of their disability.

As with the Health Service, funding will always be limited, but it is **criminal** to just exclude disabled people from this **Basic Human Right** altogether.

Begging is begging, no matter how it is dressed!

Regards

Claire Grujic (Parent of a child with Autism)