The Tricky Bits

Productivity Commission Inquiry into a Disability Care and Support Scheme

Bolshy Divas

About the Bolshy Divas

We're disability activists in the style of female masked avengers, exposing and discussing discrimination, unmet need and issues which affect people with disability and their families. Bolshy Divas use humour, art and passion to talk about the overlooked, the unfair and the subtext behind real issues which affect Australians with disability. There are no requirements to be a Bolshy Diva, just a desire to bring about change, a sense of humour and a tonne of 'bolshyness' - enough guts to talk about the issues honestly and openly. We could be anyone - we are everywhere. We rank amongst the almost four million people with disability, plus their families. We are Bolshy Divas.

About our Submission

We wanted to add a bolshy perspective, making sure some of the things we've all been talking about have been included in the Productivity Commission's deliberations. Further, this submission contains perspectives from Western Australians with disability and their families - we don't believe our view has been accurately represented in the Western Australian Government submission to the Productivity Commission.

Divas from other states have also been consulted during the development of this submission.

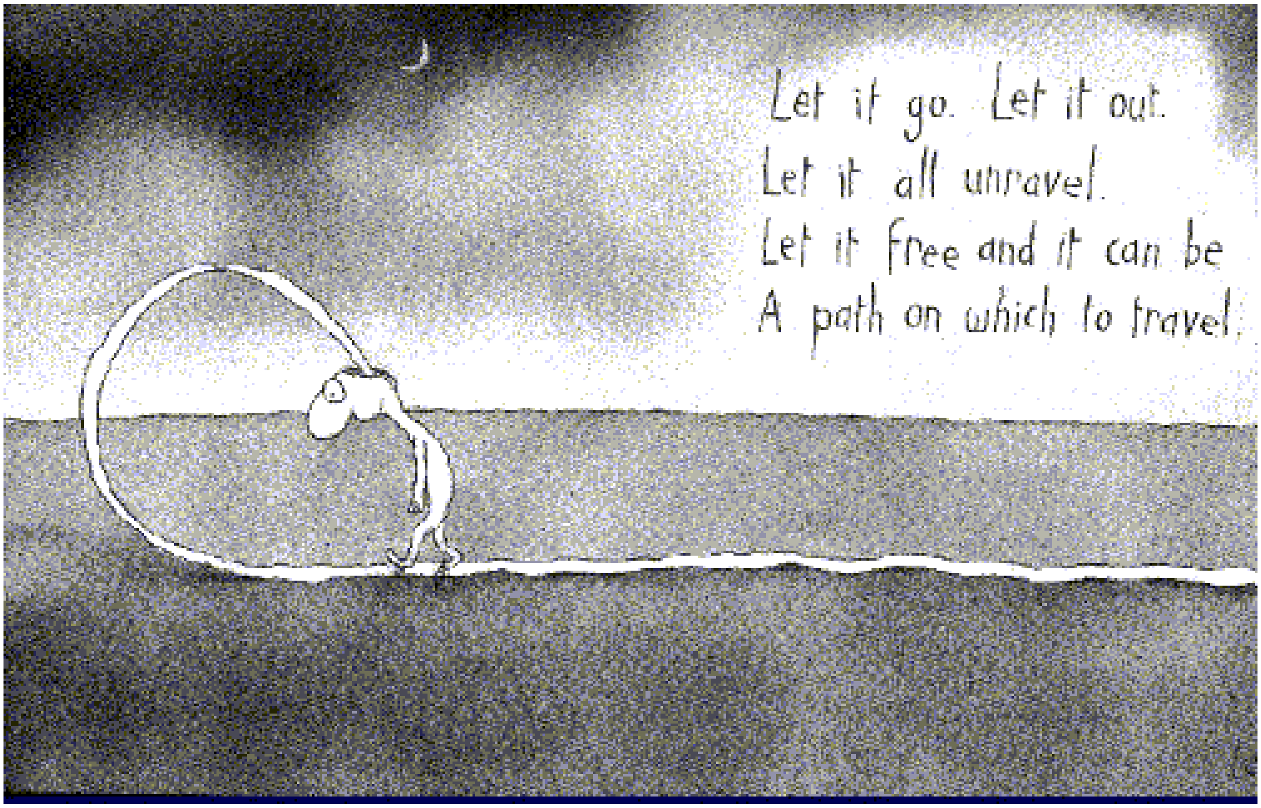
We've broken the submission up into seven parts, under the heading 'Tricky Bits' - we think they encompass some of the things it's essential to get right and some of the things we hope haven't been overlooked.

1. What's important?
2. The Devil is in the Detail
3. Having a Voice
4. Understanding What Will Make It Work
5. Avoiding Chaos
6. Changing Needs and Assessment and Safeguards, Oh My
7. Time for Change

We'd like to congratulate the Productivity Commissioners for making a difference in a point in time that we hope will significantly mark transformational change in Australian history for millions of Australians. And we'd like to thank Michael Leunig, Bolshy Diva extraordinaire, for rocking our world.

Love,

Bolshy Divas



What's important

You already know what is important, but we want to reiterate the view of many other people with disability, their families and advocates.

This scheme is for people with disability, not for service providers.
Not for governments, not for empires or private agendas.
This scheme is for people who are as individual as as their fingerprints.

This scheme is to help overcome the barriers that people have which are caused by disability, but it has to be more than that. It has to be a scheme that helps people with disability live their lives well.

We'll reiterate what others have already said. The UNCRPD needs to be the set of underlying principles when developing every part of the scheme - not just the broad outline, but in every detail of the implementation. And people with disability must be at the centre of developing, governing, monitoring and reviewing the NDIS.

People don't fit neatly into boxes, and differences aren't just caused by disability.

They're caused by culture, attitude, hopes, dreams, fears, geography.
They're caused by family, support and lack of available services and supports.
The new scheme has to be broad, flexible, and responsive to the changing needs of a diverse (non) group of people.

The Devil is in the Detail

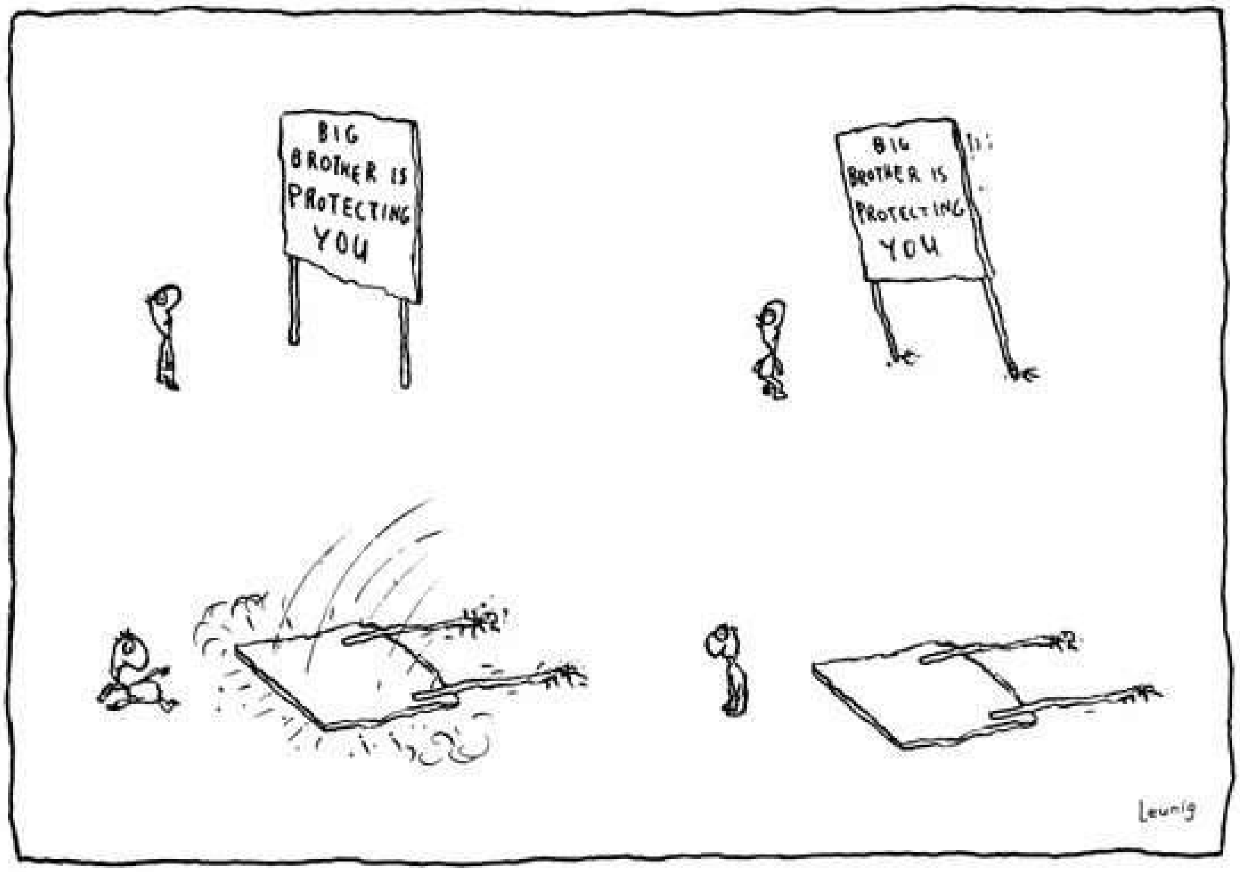
How many times have you heard this said, Commissioners?

We'll try to highlight as many 'tricky bits' throughout our submission as we can.

Here are a few.

We like our LAC system, and we also wish you'd used the term 'local area coordinator' to tell our Western Australian government that you liked it too. The system is designed really well, but 'case managers' must be local, well connected, and given the time and resources to do their job well.

In WA, each LAC is supposed to have about 50 people to 'manage'. Some have a lot more. A new office opened locally, recently, with a ratio of 9 LAC's to 400 people/families. A more realistic ratio would be 25 to 1, with a more localised approach for rural and regional LAC's who have vast distances to cover.



There also needs to be some attention given to acquitting funds. It needs to be easy, not hard...training and support needs to be available to help people manage the new systems to get the best outcomes. We should be looking at existing community capacity and how to best to fund disability organisations and support groups to provide training - and also looking at creative partnerships in communities to make this happen.

That brings us to shared management. Shared management is the West Australian alternative to direct payments funding. We used to have full self-directed direct payments funding that was allocated through the Local Area Coordinator's for anyone who wanted. But now people can only hold and fully manage the money themselves if they are small amounts and meet some other rules. The local area coordinators found the accounting and acquittal for direct payments to be taking up too much of their time. Instead of putting in training and support for people with disabilities the Disability Services Commission took away direct payments as an option and put in shared management.

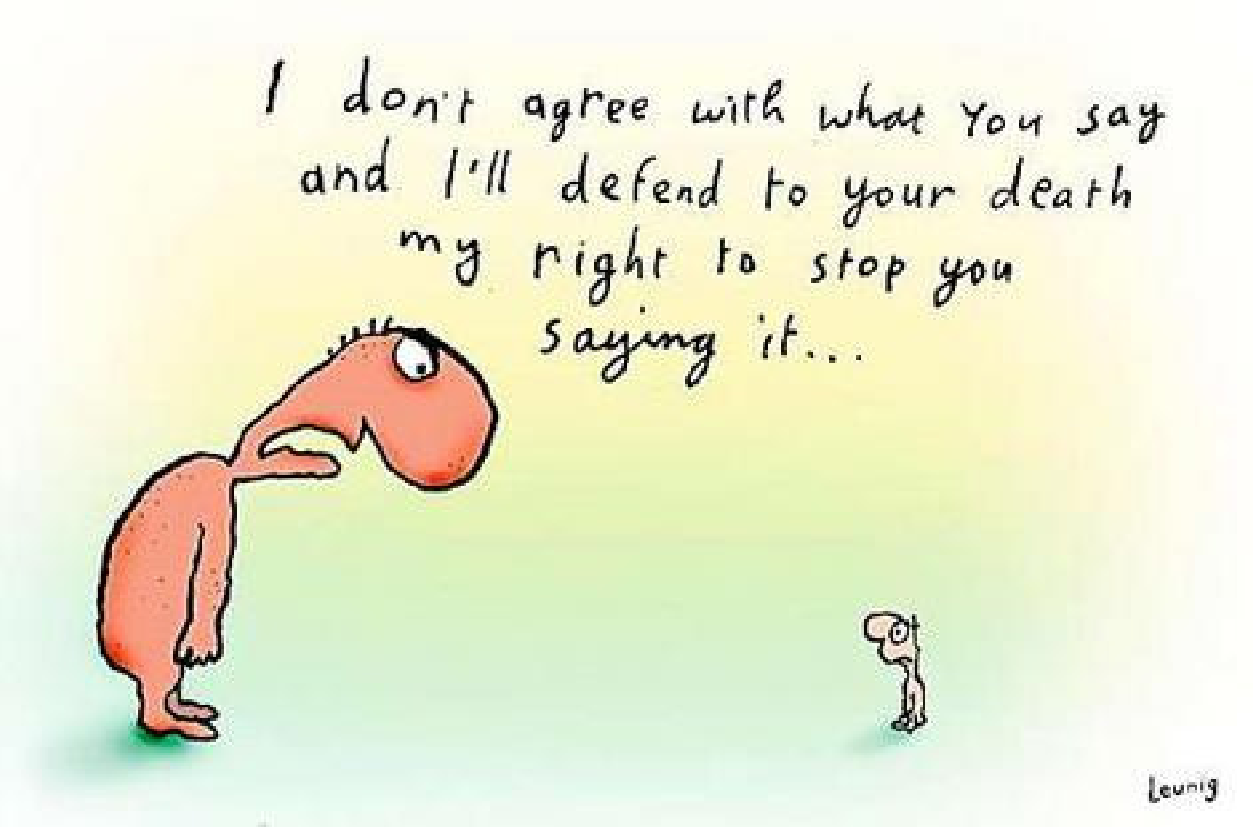
Shared management is like taking a taxi instead of driving. You are still in control of where you are going but it costs more and the driver might not always go the route you want. You can say how you want to get there, but

you don't want to kick up a fuss if they seem to know what they are doing.

There are big issues around shared management, especially with issues around conflict of interest and power. If your funding is managed by a service provider, the support staff are employed by the service provider, not the person even if the person sets the rate of pay and does the rostering.

Chained by the structures that are supposed to support you? That's not supposed to happen, but it can, and will, if new systems aren't designed and implemented carefully. If your support staff are employed by a service provider, your power or authority as an employer or participant in a commercial fee for service transaction goes out the window. You're back being - well, a 'client' rather than a person who has control over their own life.

We're not saying shared management shouldn't be an option, but shared management should be one choice in the spectrum of options for self-directed funding.



Having a Voice

In Western Australia, up to 91% of people remain unfunded. And they're only the ones who have applied.

Over 35% of others have waited over three years for essential services.

But our Government says that everything is all right.

That's why the Divas are concerned that the voices of people with disability are being lost amongst the wrangling. We're concerned that the voices of people with disability are not as loud as the voices of the service providers, the government, other 'stakeholders'. In some cases, people with disability do not have a voice at all.

That's why is it really important that people with disability - including people with intellectual disability and autism - are able to have a voice by being actively involved on the Governance board.

They should also hold the majority on the Advisory Board. Because when it comes to disability issues, the 'experts' aren't always the people who have spent the most time in the classroom.

Understanding What Will Make it Work

What will make this scheme work?

The fears that many have voiced are that it will be `like Centrelink' or `run through Centrelink'. That anonymous bureaucrats from Canberra will be running the lives of people with disability from afar, anonymously making decisions about people they don't know in regions they don't know about for people they don't care about. The fears are that people with disability and their families, who have fought for their support and services every day to date, will lose what they already have. That `the baby will be thrown out with the bathwater.'

We know you've been looking hard at what is working and why it's working.

These are some of our basic observations about `what will work.'

Are you ready?

The scheme will work if there is room for creativity and advances in technology.. If, for example, a robot vacuum cleaner would vacuum a room effectively, wouldn't it be smarter to allocate some cleaning support hours somewhere else and invest in the technology?

The scheme will work if there are high expectations that people with disability will be able to work, and achieve, to their full potential. Talk to any person currently working in the sector - they'll say things like `he's smarter than he looks' or `she surprises me every day'. People with disability are constantly undervalued and deprived of opportunities to participate in real work and other real opportunities.

The scheme will work if support isn't tied to bricks and mortar. Support should be tied to the person and portable. People should be able to live where they want, with who they want, as other Australians do.

The scheme will work if every part of it is underpinned by the Convention on the Rights of Persons with Disability...especially in the fine detail.

The scheme will work if we build on community capacity and make sure the people who are administering the scheme are the people who know, in detail, the individual and the world they live in.

The scheme will work if every person involved in implementing it can ask - what if this was about `my' life? Its about freedom - the freedom to make good or bad decisions, to make sure `everyone is in' and `everyone is with'.

Avoiding Chaos

The Divas don't have all the answers, but we have some of the right questions.

For example - who will manage the Disability Access and Inclusion Plans and the State based initiatives, like WA's (very good) Count Me In Strategy?

How will we safeguard individuals who have exceptionally high support needs, especially those individuals who do not have families?

Who will advocate for those individuals if they are chained by the structures that are designed to support them? And who will support and advocate for them if they are ready to transition to another part of their lives?

How do we protect local knowledge, community capacity, the 'baby' that we've been so carefully nurturing for years in communities, especially in regional areas?

How do we strike a balance between accountability and make sure that the structure is accountable but also flexible?

What about the microdetail? For example, we like the tier three proposal to work with a person with a disability to plan to help inform their funding allocation. But we'd also like to know that the assessors aren't limited by old beliefs and attitudes (preconceived ideas about what people with disability can and can't do), nor working to a government agenda to minimise numbers on `welfare' or carrying out other political agendas.  How can we make sure that doesn't happen?  And how can we make sure the advisory and governing bodies are aware of the `microdetails'?

How far will Australia be prepared to go when looking at `transformational change'? For example, we believe there is great potential for market development and evolution if people have self directed funding...more creativity, more inclusive supports and options. And that's good news for people living in the country, where there are fewer services and available supports. How can we think laterally and encourage innovative solutions to long lasting problems?

How would standards apply to services offered or provided by non disability organisations?

Will personal planning recognise other `tricky bits' like continuation of beneficial therapies (currently many people only get therapy until they leave school)?

Will there be room for advances in technology? Examples include developments in prosthetic limbs or ipads as communication devices for people with autism.

Will the NDIS support availability of training in values, working in a person centred way and clearly defining boundaries (who is the employer)? How will the NDIS keep a `human face' and not lose touch with the people it serves?

How will we `keep it local' and develop local, responsive solutions, utilising existing community capacity and bringing together all our community supports? How can we make sure assessments are carried out locally, by people who are directly connected with communities and families?

What about the complex `tricky bits' that come with the tyrannies of distance in our vast country? What about rural and regional workforce development and costs of travel and accommodation in rural towns?

Will detailed information be portable and owned by the person, not the state?

Will there be a trial in each state, so that there is opportunity to address their individual challenges and circumstances?

Changing Needs and Assessment and Safeguards, Oh My

One of the very tricky bits is assessment.

The Divas recognise that lots of people have changing needs and complex needs. We think the system needs to factor those needs in, especially for people with conditions likely to have comorbid conditions (like people with Down Syndrome and Alzheimers or people with autism and psychosocial disability).

We don't think the current system is ready for this, and we're worried about the certainty of adequate care in the future.

We think that it's good that assessments are proposed to be portable. We also think that people need to have access to assessments at any time because of unexpected changes in their life, not just their disability.

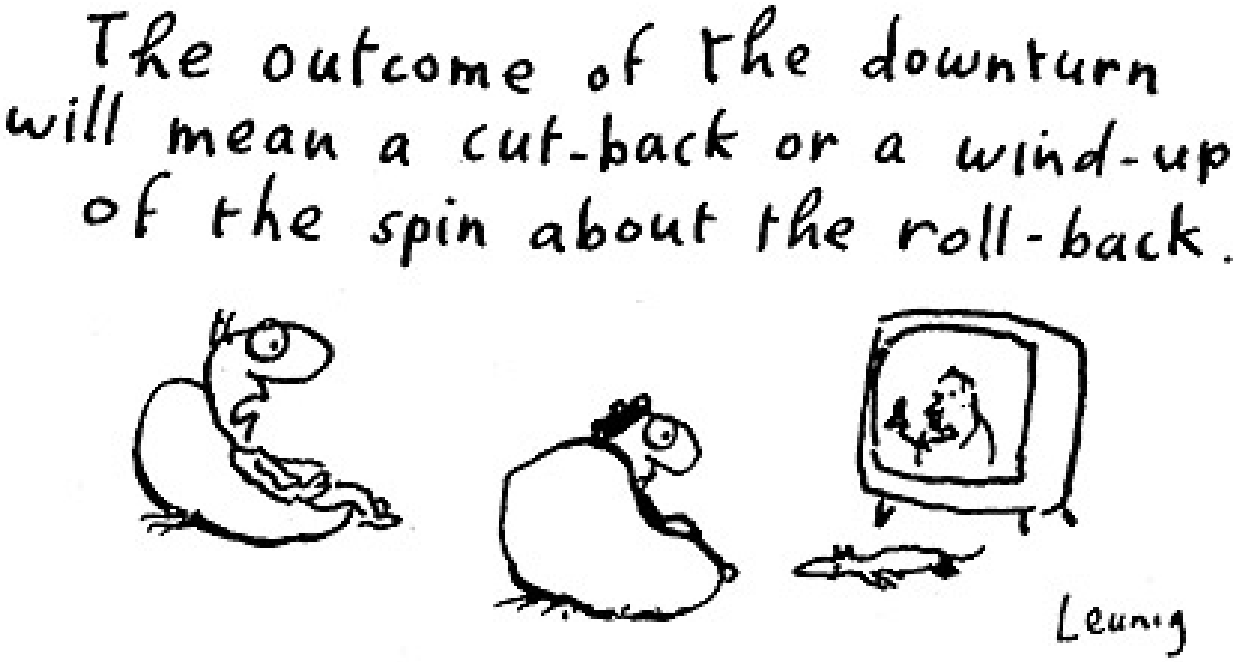
We think families' needs need to be taken into consideration. One size doesn't fit all. For many families, respite doesn't mean time away from your child, but time for the family to have a break together. Availability of `family assessment' for informal carers, ie parents, is a good idea, because families are complex and each family unit has complex needs. If this could be carried out in a way where there are no value judgements and where the person with disability is at the centre of the assessment, it would be very valuable for families to better support the needs of the family member with disability.

In the report, it says people may appeal on points of law but not on merit. We think there should be a clearly defined appeals process for assessments that people feel are assessed unfairly or inaccurately.

And development of the safeguards for the assessment system really need to include input by people with disability and their families, especially when it comes to satisfaction about outcomes (funding allocation, appeal process, complaints process)

How do you assess a person's needs? If you think back to the five most important things that have happened in your own life, then assess what you needed to make it happen, you'll understand the `complexity of need'

All people need formal and informal support to achieve their human rights, needs and aspirations in ways that fully include them in the community. Some people need more support than others.



Time for Change

The Divas think the Productivity Commissioners have done a fantastic job. It has been very bad for a very long time for people with disability, and the tragedy of it has been that for a very long time nobody knew, nobody cared.

This has changed. Bill Shorten started it by publicly speaking about the issues which had affected millions of Australians. Other stakeholders started it by dreaming aloud about what could be, what should be and how it could work. Advocates started it by making sure that the voices of people with disability could be heard and that their rights were able to be upheld. Our Government started it by commissioning the Productivity Inquiry.

We have all the tools we need to make sure we do the right thing. To include all of our Australian citizens in every aspect of Australian life. Its been a long time coming, but its now time.

It's time for Australia to catch up with the rest of the world.
It's time for our governments to stop squabbling at the expense of people's lives and get on with the job at hand.
It's time for our decision makers to show us that they care about all of their citizens.

As Ramp Up Editor Stella Young said at the National Disability and Carer Congress - 'We want people to have what they need to be who they are.'

In this story, we said that it's important that Australia asks people with disability and their families the right questions.

But there is only one right question, really.

If we answer that correctly - Australia will be immensely richer. Not just in material ways, but in the colour and flavour of diversity and inclusion, which makes up an entire nation of citizens in a world that's devoid of apartheid thinking and separateness.

Here's the question.

What makes a good life for people with disability?

We look forward to the answer of the Australian Government.

Love,

Bolshy Divas