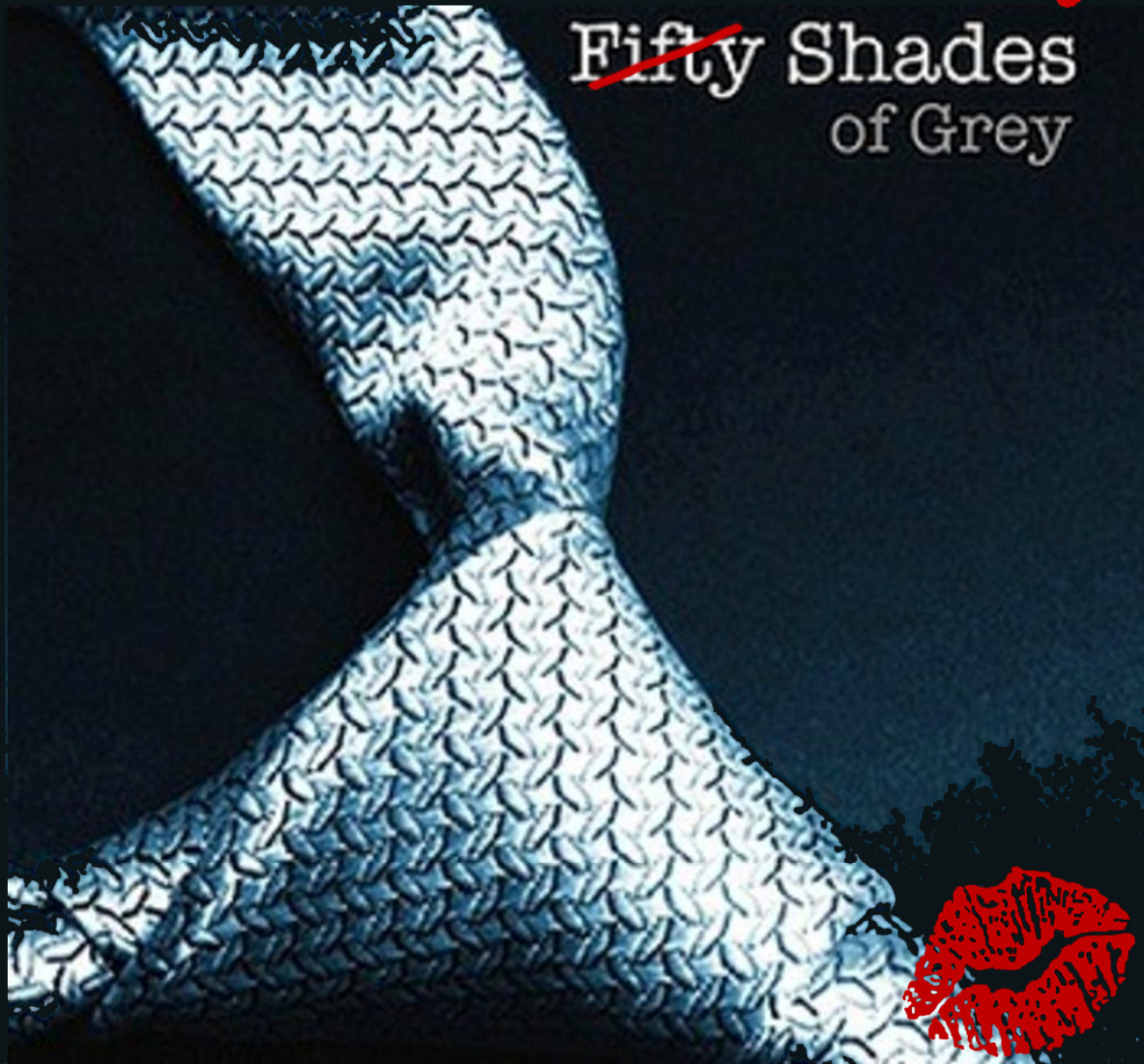


One Hundred and Fifty

~~Fifty~~ Shades  
of Grey



A completely serious submission to the Senate Inquiry into the  
National Disability Insurance Scheme legislation - Bolshy Divas

# Introduction

'How many Shades of Grey?' asked the Tasmanian Diva, raising one perfectly sculpted eyebrow.

The rest of the Divas looked slightly stunned. It was Anastasia's first Diva Submission, and as the youngest of the Divas, she'd had little experience. Still...it was hardly what they'd expected.

Anastasia crossed her arms and looked at the rest of the Divas defiantly.

'One hundred and fifty,' she said. 'The NDIS Bill has one hundred and fifty pages, and let's face it - how bored will they be, reading all these submissions? At the very least, we can spice it up.'

'One Hundred and Fifty Shades of Grey,' said a Queensland Diva musingly. 'And, Anastasia, have you taken liberties with the Powers of the CEO chapter?'

Anastasia blushed. 'He has a partner - I think - and besides, its fiction,' she said defensively. 'But...it's a good title. Because none of us are black and white, we're complicated people with complicated lives, and this is a hundred and fifty pages of an attempt to put shades of grey into black and white, if you get what I mean.'

'And will it be raunchy?' asked a South Australian Diva, eyeing Anastasia over the top of her glass of Moet. Anastasia squared her shoulders.

'Probably not,' she admitted. 'But if you're looking for a tale about power - who the dominant powers are, and who has the smallest voice - you've got it. And I can guarantee, at the very least, it will be written better than the original.'

The Tasmanian Diva nodded.

'Not hard,' she conceded. 'And just because we're invited to make a submission - we don't have to be...well, submissive. It's our lives, after all. And isn't that what disability reform is supposed to be about? Changing the balance of power?'

The Divas nodded, and turned to the first page.

# Obedience

**'Obedience:** The Submissive will obey any instructions given by the Dominant immediately without hesitation or reservation and in an expeditious manner. The Submissive will agree to any activity deemed fit and pleasurable by the Dominant excepting those activities which are outlined in hard limits (Appendix 2). She will do so eagerly and without hesitation - **The Rules, Fifty Shades of Grey.**'

Anastasia threw down the book. It was rubbish, even for a spankbuster - poorly written, with questionable moral concepts and an even poorer story line. But the alternative reading was far less palatable. She sighed, and picked up the Document.

The National Disability Insurance Scheme Bill, 2012, read the front cover. 'A Bill for an Act to establish the National Disability Insurance Scheme, and for related purposes.' Hardly scintillating reading. She picked up her pen with a sigh, and started making notes in her Diva Diary.

'The timelines are ridiculous,' she wrote, then crossed out the words. They knew that, of course. There was an election looming. She tried again.

'Nobody except a lawyer or a service provider with a PhD and a battery of intelligent staff members could understand the terminology.' Then paused. Should a government organisation be expected to put EVERYTHING in Easy English? Not just the overview, but the whole legislation? They're new at all this, after all. Probably had to google who to contract to provide an Easy English translation. She bit her lip, lost in thought, and unbuttoned the top button of her blouse to add a little readability.

A pink post it note caught her eye, and she read again the NDIS High Level Principles - 'g. Provide people with disability with better information and support to enable them to make informed choices and exercise control and choice over their care and support'. Wait. If people couldn't understand the information in the first place, aren't we disobeying our own Principles even before we make the scheme up?

Anastasia thought about it. If the people this scheme is for can't understand the prospective rules, isn't that wrong? If a new reform was being designed for, say, people from Turkey, wouldn't it be logical to translate it into Turkish? And wouldn't you have to allow extra resources and time for an interpreter to ask the right questions?



She wrote; 'Think about this.

There are a nation wide shortage of 'interpreters', the people who are very good at asking the right questions and interpreting some complicated legalese.

Some of the disability peaks have done a reasonable job (with some notable exceptions), but their memberships are limited and city centric.

Some of them have members who are articulate and passionate about advocacy in their own right - and they will make their own submissions. But who - tell me, who? - has read the question about the proposal for a person with disability to have to request permission from the CEO of the NDIA to take a holiday, and then has sat down with a person with an intellectual disability to say 'Hey, Tim? How often do you go on holiday? Do you stay in Australia? Would you like to go overseas, and how long for?'

Anastasia thought about her friend Tim, who has Down Syndrome. He would agree to any activity deemed fit and pleasurable by his service provider, and would probably need a great deal of support to answer this question. Because we people with disability are trained to agree, eagerly and without hesitation - to obey. We need support, and time to think about these rules which will impact upon our lives.

Our lives, our rules.

She wrote down the words

**INVOLVE US - ASK US IN A WAY WE UNDERSTAND**

and underlined them three times.



## Easy English Isn't Easy, but...

Anastasia threw her diary across the room and reached for the butcher's paper. If you're going to make a point, you might as well do it in bold, black artline, and lead by example, with stamped on lipstick kisses and scratch and sniff stickers.

But this was trickier.

This was an attempt to write in Easy English. She changed over to her dominant hand and began to write;

'There is a law called the Convention on the Rights of Persons with Disabilities.

It is important.

You are making a Bill.

The Bill needs to tell us how it will make all the parts of the Convention happen.'

Okay, it was harder than it looked. Anastasia felt sorry for the guy at FaHCSIA who'd had the awful job of trying to cobble the Plain English overview together. But she really wanted to know how the whole of the Convention - that important stuff that wasn't really included properly in the Draft Bill - was going to be enacted. We'd promised to do that stuff, right? At the UN, which is kind of important. And there are other issues - the mainstream supports that we keep hearing about, which aren't really there. There are assumptions that people will be supported in health and education and employment and in a bunch of other policy areas - but nothing points to the National Disability Strategy, the policy that is supposed to make the whole thing work.

That Convention. That was a Hard Limit, really. The Legislation Must Be Consistent With the Convention on the Rights of Persons With Disabilities. Because it's so easy for bad practice at the bottom to creep in when its not all clear at the top.

Anastasia sighed. Even her THINKING was colored by the spankbuster. But the concept of Hard Limits wasn't a bad one, really.

In Fifty Shades of Grey, Christian Grey says, 'So, limits. These are mine.' He hands Anastasia - weirdly, the heroine has a Diva name - a piece of paper marked 'Hard Limits'.

The inclusion of the CRPD Principles is a Hard Limit, Anastasia decided. And there will probably be more.

**Hard Rules**, she wrote.

1. **We Must Be Involved.**
2. **The Legislation Must Be Consistent With the Convention on the Rights of Persons With Disabilities.**

Not a bad start. Even if it wasn't in Easy English.

## Involving Us

'My belief is to achieve success in any scheme one has to make oneself master of that scheme, know it inside and out, know every detail.'

— E.L. James, *Fifty Shades of Grey*

Took a lot to find that quote. *Fifty Shades* is lacking in insightful commentary about engagement, she mused. Anastasia snapped shut the book and thought about what it meant to be involved.

In the world of the disability sector, there's a lot of doing 'for' and 'to' rather than 'with'. And there are a bunch of master-and-slave relationships, if you think about it - why would you speak up if you're afraid of losing your support, losing your funding, being worse off? People in our sector have a history of being suppressed and down-trodden, and the prospect of being 'actively involved' is something we're not used to.

But it can't work unless we ARE involved. That document, the CRPD...it says we need to be. It says we need to be players in this game of chess, rather than the pawns. But how can we make sure people with disability are respected and recognised as players in this game?

Anastasia thought about all the words used in the disability sector. People aren't employees, they're participants. Willing, submissive, participants. They're consumers, or clients, but seldom are they people. And they are almost never masters of their own destiny, let alone disability care and support schemes.

There's the question of disadvantage - if you're disadvantaged by disability to begin with, how will you be actively involved? And what will happen if things go wrong? She looked at the Document again, and noted that advocacy is missing from the Legislation.

Its like a safeword, advocacy. You know that it is there, and that you can call out when things get too heated. That there's a fall back position to stop us all leaping off cliffs like lemmings or being beaten by tall men wielding riding crops.

So where the hell is it? And should it be in the legislation in the first place?

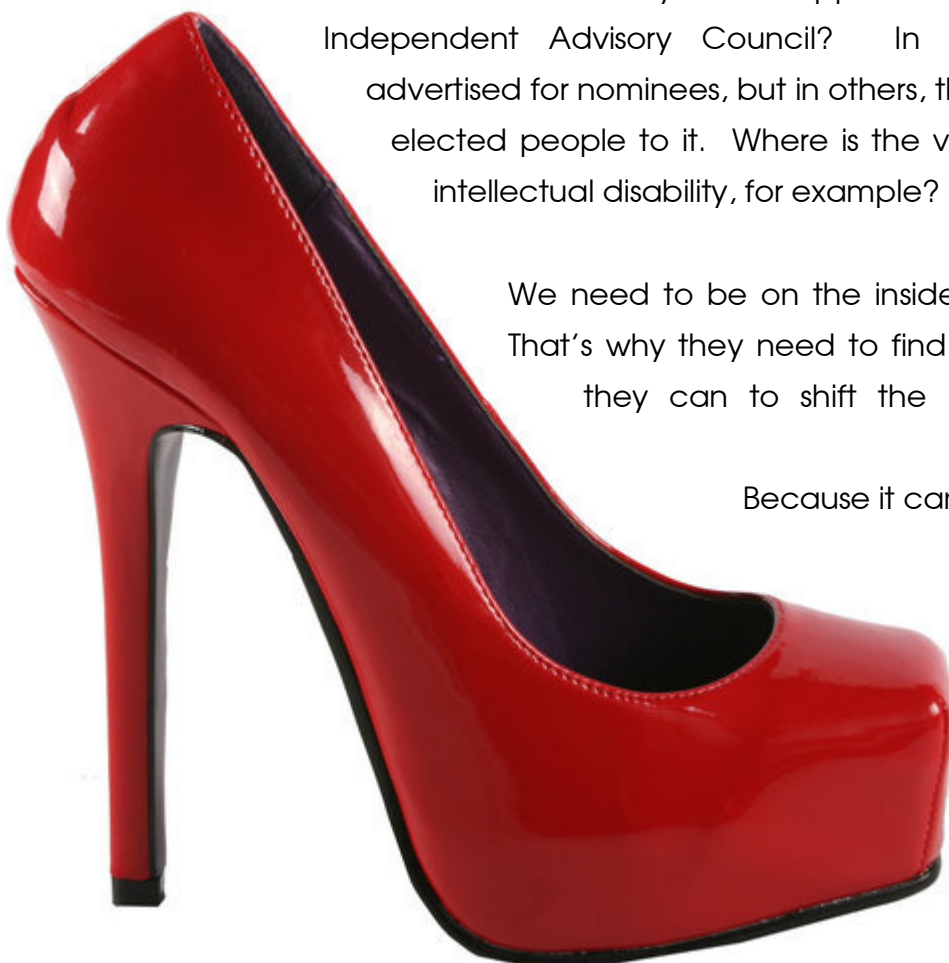
Well, yes. Provision for the funding of people with disability should be in the legislation, because if its not there, who will support them when they're engaging with the NDIA? We're not just talking about people with intellectual disability - are the NDIA going to have their own band of interpreters for people with intellectual disability who come from non English speaking backgrounds? What about people in prison, or people who are homeless? People living in the Top End? Or other people who, for some reason or another, come into the category of 'One Hundred and Fifty Shades of Grey'?

What about employees, and the Board? Our public sector employment sits at about 1.5%, and we have the lowest employment rate of any OECD country - is it a good idea to exclude board members with disability because they hold a government position? Sure, Christian Grey of the FaHCSIA Fines Enforcement Department might have a conflict of interest, but what about your garden variety local government councilor, or your suburban librarian? I bet they haven't thought about how people with intellectual disability could be employed, thought Anastasia, biting her lip. Its outside of their scope of thought.

What about the way we appointed people to the Independent Advisory Council? In some states, they advertised for nominees, but in others, the government elected people to it. Where is the voice of people with intellectual disability, for example?

We need to be on the inside of it for it to work. That's why they need to find as many ways that they can to shift the balance of power.

Because it can't work without us.





## The Cost

'My inner goddess looks like someone snatched her ice cream.' E.L James, *Fifty Shades of Grey*

Anastasia grinned. The *Fifty Shades* book just accurately described the experience of so many people with disability - find the perfect wheelchair, realise you're not eligible for funding. Find a job, realize the cost of a taxi will be more than your weekly wage. The costs of disability aren't always obvious to people on 'the outside', those who think that the costs of disability are associated primarily with capital expenses like equipment and some smaller items like medications - but the truth is, it mounts up. And you're left looking like someone snatched your ice cream.

She grabbed her Diva Diary and drew a giant \$\$\$ sign on one page, reflectively. If they weren't careful with the legislation, it could cost people with disability more than they could afford.

Think of Centrelink. Many people are able to meet their commitments when it comes to the transactional elements, those 'essential' meetings and appointments, but a lot of people can't. And if you dug down a bit further, you'd find that they're the people we're talking about now. The people who live a bit out of town, who can't afford a taxi. Or can't get there, because the appointment was scheduled at nine o'clock and their disability support worker doesn't start til ten. Or because the appointment time arrived on a piece of paper in the mail, which they couldn't read, because it wasn't accessible to them, or because they had a language other than English, or because they didn't have the right support at the right time in the right way.



The dollars. If they weren't careful, they'd think means testing was the way to go - but every person with a disability in Australia knew how big a trap THAT was. When it's cheaper to stay home and receive reasonable and necessary funding and equipment, why would you work?

That was another bit that was missing, Anastasia thought, chewing the end of her pencil. The legislation doesn't expressly provide for funding to be going to those other, necessary supports. The interpreters, the mainstream and specialist organisations, the other entities that could provide a good (and often cheaper) alternative for many people. And how would people know about their options? Where does it say that dollars will go to building capacity, not just in the community and in mainstream organizations, but to people themselves? We don't want a giant, Centrelink like bureaucracy, because that isn't going to work for many of us. It looks like, and is flavoured like, a big hierarchal structure. Talk to any Centrelink disability advisor about how well that works for the complexities that surround the lives of people with disability. The legislation, as it is written, doesn't leave room for those little organisations who have grown their capacity in response to need over years and years - those tiny advocacy organisations, those family support organisations. They're missing from the big picture.

Penalising people for having a disability, all those little costs. They add up. The costs of assessment, for example - who will pay those? If, as proposed, a person is forced to enter into a court of law to pursue a compensable claim - who will pay their costs if they lose? And who will pay their counseling fees when they are broken by the process? And what about examinations? People on the outside of this life don't know, for example, that people with physical disability in some states pay for ACROD parking, and that they pay up to \$420 per annum for a specialist driving assessment, and a host of other disability related 'additional costs'. Would it be fair to penalise people more?

That was a stated principle early on, Anastasia realized. Nobody should be worse off. She scrawled it into the Hard Rules - **Nobody Should Be Worse Off**. Because penalising people with disability even further would, indeed, be a cruel and unusual form of torture.

# Dominance and the Powers of the CEO

## **From Fifty Shades of Grey - Sleep:**

The Submissive will ensure she achieves a minimum of seven hours sleep a night when she is not with the Dominant.

## **Food:**

The Submissive will eat regularly to maintain her health and wellbeing from a prescribed list of foods (Appendix 4). The Submissive will not snack between meals, with the exception of fruit.

## **Clothes:**

During the Term, the Submissive will wear clothing only approved by the Dominant. The Dominant will provide a clothing budget for the Submissive, which the Submissive shall utilize. The Dominant shall accompany the Submissive to purchase clothing on an ad hoc basis. If the Dominant so requires, the Submissive shall during the Term any adornments the Dominant shall require, in the presence of the Dominant and any other time the Dominant deems fit.

## **Exercise:**

The Dominant shall provide the Submissive with a personal trainer four times a week in hour-long sessions at times to be mutually agreed between the personal trainer and the Submissive. The personal trainer will report to the Dominant on the Submissive's progress.



## **Personal Hygiene/Beauty:**

The Submissive will keep herself clean and shaved and/or waxed at all times. The Submissive will visit a beauty salon of the Dominant's choosing at times to be decided by the Dominant, and undergo whatever treatments the Dominant sees fit.

## **Personal Safety:**

The Submissive will not drink to excess, smoke, take recreational drugs, or put herself in any unnecessary danger.

Anastasia finished the page and burst out laughing. No Diva would submit herself to that kind of treatment by any man, and she doubted that any actual Submissive would, either. And as for people with disability...she reached over for the Document and flicked to the page that outlined the Powers of the CEO. And other pages that talked about Power and Control.

Four minutes later, she was no longer smiling and was rewriting the Fifty Shades passage in her head.

### **Personal Holidays**

The Submissive shall not holiday for longer than six weeks, and if they do so, their Plan will probably be suspended.

### **Life Plans**

The Dominant will approve a Life Plan and if they do not, the Submissive will not be permitted to live their Life. The Dominant shall own the Life Plan and permission must be sought from the Submissive if they wish to alter or adapt it (including in times of crisis or if they change their mind about their Life Direction). The Submissive must share every aspect of their Life, even if it is not relevant to the Funding. The Plan shall be owned by the Dominant and all ownership of information shall hereby be revoked by the Submissive.

### **Privacy**

The Submissive hereby gives up all right to privacy to all of their information and allows the Dominant to disclose private and confidential information about their lives to any government department for unspecified purposes.

It would be funny, but it wasn't. This was real life. Should people with disability be allowed to go on holiday, and should they have to ask permission? And what of ownership of plans? Why should the CEO have to \*approve\* the Plan? Who will be approving the CEO's Plan? And what happens if something happens to the person with disability - something usual, like a transition or a crisis? Would a new plan have to be put in place, and what would happen to that person in the meantime? Would they stay in hospital, or be homeless, or be otherwise unsupported?

Another passage for the Hard Limits. Nuff said.

## The Tricky Bits

‘Do you want me to spank you, Anastasia?’ - E.L. James

‘What the HELL are you writing?’

Anastasia jumped. The Queensland Diva was standing directly behind her, reading over her shoulder. Anastasia blushed.

‘That’s rude, you know, reading over someone’s shoulder,’ she murmured. ‘How are you?’

‘Damp,’ retorted the Queensland Diva, and sat down beside Anastasia. ‘Weren’t you writing a submission to the Senate about the Legislation?’ She glanced, amused, at the open copy of Fifty Shades of Grey.

Anastasia snatched the book up to her chest defensively.

‘I am,’ she said defensively. ‘Do you want to give me some tips?’

The Queensland Diva smiled. ‘I could flood you with a million of them,’ she said. ‘But have you asked how reporting will work? And how often people should account for what they’ve spent money on? And what services and supports will need to be provided for this? And how you decide if something is reasonable? And have you asked about safeguards for people to make sure they’re not ripped off by providers or suppliers who know its government money?’

Anastasia swallowed hard.

‘What about the role of parents when it comes to being nominees? Can they be both a plan nominee and a parent nominee? And how do the good parents avoid being forced to defend everything they do, whilst making sure that people who are not acting in the child’s best interest are unable to use the system for their own purposes?’ She looked at Anastasia and smiled. ‘You asked for tips.’

‘Yes,’ said Anastasia. ‘But they want suggestions, right? And they want us to point out



the bits that don't make sense, or aren't clear. Like the lack of clarity about how the role of the nominee might be different from a legal nominee. And like the lack of referencing human rights legislation when talking about decision making - supported decision making as opposed to substitute decision making. And the registered providers of support stuff...'

The Queensland Diva looked thoughtful. 'Conflict of interest stuff?'

'Oh, yeah, baby,' Anastasia pointed to the legislation. 'Can you fund a scheme, provide information, manage funding and then provide supports? All at the same time? Probably a bad idea. And what does the legislation say about unregistered service providers and plan managers? If you can work it out, you're a better woman than me.'

The Queensland Diva looked hard at the legislation. 'Can't see it in there,' she conceded. 'And that's a problem if the plan manager needs to be a person who is close to the individual, or if they need to be culturally aware of their circumstance, or if they are one of two Aboriginal people in the far north of Australia. What if there ARE no registered providers of supports in that area?'

'Exactly,' said Anastasia.

The Queensland Diva slicked back her hair and patted Anastasia gently on the head. 'You've been spanked enough,' she said. 'Good luck with it. What a horrible job.'





## Planning our Lives

'PS: I also note that you included the Stalker's Anthem, "Every Breath You Take." I do enjoy your sense of humor...' — E.L. James, *Fifty Shades Darker*

Anastasia chewed the end of her pencil thoughtfully. This was the tough one, although other people didn't see it that way. It was a good thing to have a plan, right? Because you can't plan your life - and your support - without a plan, right?

But how many people in the real world have plans? And how many people have plans that have to be *approved* by other people?

She rang the South Australian Diva.

'Dahling!' The Diva said brightly. 'How's the submission coming along?'

Anastasia rolled her eyes at the phone. 'Horrible,' she muttered. 'But...tell me, Diva, do you have a plan for your life?'

'Of course,' said the Diva.

She rattled off a list of activities that included high teas, advocacy activities and drinking copious amounts of Moët, but Anastasia was already shaking her head.

'No,' she said. 'What will you be doing two to five years from now?'

Peals of laughter echoed down the phone, and Anastasia hung up gently. Unhelpful.

There were a whole bunch of issues, but working out how you put them into legislation was another thing. It was a good thing to have a life plan, but a bad thing if someone else decided whether you should set goals in your plan and KPIs to measure

success. Or was it? Do other people have key performance indicators to measure the success of their lives?

How much flexibility is okay? Anastasia looked at the Fifty Shades book, and grinned. But it wasn't a bad analogy, actually - do people plan out their sex lives, or do they just go along for the ride? Oh, you might decide to plan on buying the candles and the flowers and even the Elton John track - if you were seriously warped - or maybe even the leather swing and the riding crop, but would you plan out your whole sex life for the whole month? Wouldn't it kill the spontaneity in your life? And would there be OUTCOMES?



What if someone key to the plan dies? What if you move house, or need something that isn't in the plan? What if you have a medical condition that suddenly deteriorates - would you need a whole new plan? And what if you suddenly needed reasonable and necessary supports that were NOT in the plan?

Then there's the biggest issue - the issue of unreasonable risk, and who decides what unreasonable risk is. Because we're all grownups, right? But we learn by making mistakes, and a lot of people with decision making disabilities have a worrying history of being treated like children, with no opportunity to learn. The dignity of risk, muttered Anastasia.

And what about ownership of information and who can change the plan, and when? That's another hard limit, right there.

**Plans and information must be owned by the person.**

# Making the Judgement Call

„Maybe those guileless eyes can see through me. Control is my middle name“  
— E.L. James

The hardest pieces to articulate are the most important, thought Anastasia desperately. And the job they've been given - putting one hundred and fifty shades of grey into two colours, black and white, is nearly impossible. Within the timeframe, without our active involvement, without us taking this Bill - she looked at it with distaste - and laying it over every aspect of our lives to see if it will fit.

She unclipped her biggest, boldest texta and scrawled in pink - Power and Control.

Because that is what it is about, really, isn't it?

Who is going to make those judgment calls? And some other questions...

Who will decide what is value for money? The short term benefits are often judged by people who don't have any idea of long term benefits and outcomes.

Who will decide that someone needs another assessment or another examination and who will decide how it is paid for?

Who will decide - if people with spinal cord injury are not listened to, and if the decision is made to force people to pursue compensation for potentially compensable consumers - when compensation must be pursued at all costs, or when the cost - emotional, financial or potential of loss - is too great?

Who will decide what to do if people with disability have a complaint against a service provider? How are we going to currently uphold our obligations under the CRPD to protect people from abuse?

What about the elephant in the room - aged care? What will become of those people who have disability acquired via causes unrelated to aging, and how will they be supported in an unsupportive aged care system without specialist supports? Sixty five is not very old, and there are many productive members of society with severe and profound disability who will no longer be able to participate fully in Australian life



if they are only supported by the aged care sector.

Who will decide how people are supported through an unwieldy Administrative Appeals Tribunal case, and who will be making the decisions about whether a person has a fair or unfair case? Will people with disability be represented on the Tribunal? Will there be a disability Ombudsman, or will there be something similar to the SSAT?

And if you're no longer allowed to manage your funding if the NDIA thinks that would be too big a risk - who will decide, and based upon what measures?

And lastly - is there anything in the Bill that provides lifelong certainty? There needs to be an understanding that there is no model of disability care and support, wrote Anastasia, because there is no model for life. All we should be doing is putting a frame around the outside of a picture - a picture of a good life for people with disability and their families. And the Bill should be that frame.

How to finish? Anastasia picked up the Fifty Shades Trilogy, threw them violently (and with a sense of relief) across the room, then scrawled the last few words.



- finis