1. SAVE OUR NDIS with El and Pauline

**Pauline**

3CR is proud to acknowledge the Wurundjeri people of the Kulin nation; traditional owners of the land from which we transmit people powered radio. You are listening to Rest Is Survival. A 12 hour special for 3CR's Disability Day broadcast. I'm 3CR's Disability Day worker, Pauline Vetuna. To kick off our day of programming, you're about to hear from Elle Gibbs. An award winning writer with a focus on disability and social issues. I caught up with them in November to get their insights on the upcoming and as a review and reflections on the theme of this year's broadcast. The NDIS review was recently announced by the federal government. Could you tell us what the NDIS review is, and why it's been called for?

**El**

Sure. I think there are a couple of different reasons. There's a pragmatic reason and then there's a political reason. The pragmatic one is that, there was always going to be a 10 year review of the NDIS. Originally, the Productivity Commission was going to do it, kind of looking back at their original report, and their review that they did, kind of halfway through in 2017.

**El**

And then there's a political reason. Labur, when they went into the election, in response to the coalition's "Oh my god, the NDIS is so out of control", said, "Oh, we'll have a big review, we'll find out what's going on". So that's part of that reason. Labor's taken it out of the Productivity Commission, and given it to an independent group of people, a mix of people, mostly non-disabled people.

**El**

But there's also some very good people in there who know a lot about the NDIS, including two disabled people who both use the NDIS for their support. So I think that's really important. I think the review is to do a number of things. It's an answer to criticism from people talking about the cost of the NDIS -- "Oh, we've got to wait till the review comes out". So that's the political answer. I think part of the review is really genuinely trying to get to the bottom of what is happening in the NDIS.

**El**

Because disabled people and families have said so clearly that things aren't working. So I think there's genuinely a desire to fix that. And then there is the politics of it, and the raw politics of the renegotiations with states and territories that are going on at the moment, and will be finalised next year. So that is about money, you know? That is about who pays what for the NDIS, and some very hard nosed negotiations between the federal government and the states and territories.

**El**

So all of those things are tied up in that. But I know that Bruce Bonyhady, who's one of the people heading up the review, was one of the original people behind the structure of the NDIS. He's an economist. He's a parent of two adult people now who are with intellectual disability, and he has a genuine interest in the NDIS working. But he also has a very particular viewpoint on the model of the NDIS, and why it should work in particular way.

**Pauline**

Speaking of the political reasons for the NDIS review, it was hard not to notice the response by the usual neoliberal and conservative establishment partners in the media, to the announcement of the review. And I think even Shorten emphasised the cost of the NDIS during the announcement. Could you tell us about your observations of this response?

**El**

Look, I think a lot of the current conversation is a continuation of the previous few years of conversation. You know, we had a minister for the NDIS. You know, Stuart Robert, who ran around saying that we were all spending NDIS supports on sex yachts (and I'm not actually joking). He said that in a number of interviews, and tried to bring in independent assessments as a way of both changing the NDIS forever and getting people off the NDIS. And then since, it didn't help that, Labor before the election, said “there's no problem with costs of the NDIS and everything's fine”. And then they got into government went “Woops, uh yeah. There’s actually a problem”. And both the treasurer, even the Prime Minister, have weighed in now.

**El**

And I think some of it is a concern, like there is a concern about what's happening, but I don't think they under- I don't think people who talk about the cost stuff, understand what costs so much money. So I went and had a look because partly I wanted to know, and the NDIS does release quite a lot of data. So I went through the spreadsheets and looked at what the NDIS spends money on in New South Wales and the ACT to start with. The biggest and the smallest state and territory.

**El**

The biggest cost to the NDIS is group homes. That's the biggest cost. So they're not nice places to live. That’s the biggest cost, it's like 25 to 27% of the NDIS costs. The next biggest one is support workers. So that's what's called ‘assistance for self care’. The next biggest one is assessments. So all those damn reports that everybody has to get to justify everything, that cost between 4 and 6% of the NDIS. The next biggest costs are things like support for special schools. So transport, personal care for kids at special schools, huge cost. Plan management support coordination, which is gatekeeping if you have the NDIS. You know, I explained it to someone in government as like, imagine if the Centerlink said, “right, we're going to open up for private providers.

**El**

And to get the DSP, you have to have a for-profit company with an app that you have to use, who takes a percentage of your DSP to allow you to have any money and decides what you can spend it on, and can refuse it anytime”. And everyone laughs and I'm like, but that's the situation with plan management and the NDIS. Currently it's just a for-profit lurk, mostly. And that is between about 1.2%. Support coordination is another 2%. So you can see very quickly, it's not holidays. It’s not even wheelchairs, it's not home modifications, it's not cleaning, it's not anything that people say in those articles. It's very basic disability support. And while I have enormous issues with propping up a separate disability support system, like group homes, like special schools, they're not fancy shit. You know, and they are mostly used by people with intellectual disability.

**El**

So I think that a lot of the cost debate operates as though we're having two very different conversations. And it's not actually a debate about, they go “Oh, but the really disabled people are fine”. I’m like, “but that's what cost the most money! Is supporting people with the highest support needs”. So you can't say on one hand “oh, it's only for the really disabled”. But that's actually what costs the most money! And so you have the Australian Financial Review, and then these special investigations by Sky News, talking about, you know, the influx of children with autism. And that's the problem. They're mostly on packages of about $13,000, which is what, speech therapy once a fortnight for a year? That’s it. Like, it's not a lot of money.

**El**

But I do think that the reason they attack us and the reason they attack disabled people is because of the reasons they've always attacked disabled people. You know, we're not actually seen as worth spending money on. And I think that's the prejudice and the ableism behind a lot of it. We don't have these discussions about defence. We don't have these discussions about tax lurks for landlords, and we don't have these discussions about subsidies for coal mines. We have them about disabled people, and particularly about people with intellectual disability. So yeah, I think it's shit. But I think there is lurks in the NDIS and problems with the for-profit providers. And I think there are big problems with the building of a huge separate disability system. That particularly is for people with intellectual disability. I think that's a huge problem. But that's not what the Australian Financial Review or Sky News it's talking about.

**Pauline**

There is so much ableism in discussion of NDIS participants. And this reminds me of your recently published article, “The NDIS is an investment in a decent society, not a burden on the budget”. Could you talk a bit about that piece and the arguments you're making in it?

**El**

Sure. I think part of that came from a broader piece of writing that I'm trying to do that I never have time to do. Which is in response to criticisms of the NDIS from the left. One of the things I got really angry about last year was that in the fight against independent assessments, we were left to be the ones doing the fighting. Look I don't get NDIS support. I'm one of those people who's been left out from the NDIS. But I fought really hard for the community, because I know what the independent assessments would mean.

**El**

And I didn't see the wider civil society, particularly on the progressive side of politics, joining with us to fight those campaigns. And I often see people on the left talking about “Oh, the NDIS is hopeless. It's all just for-profit privatisation. We have to go back to the old system. We're much better off with block funding. There's no reason for it to be like it is”. And I get very concerned when I read and hear conversations like that. And I hear it from unionists, and from scholars and regular rank and file, you know, left people really misunderstanding what the NDIS means.

**El**

So part of wanting to write, particularly writing for Tim Dunlop’s newsletter, it has a wide audience, a progressive audience. So it's helpful for me to write a bit about that, thinking about the NDIS as part of our social infrastructure, which it is. And it was set up so that if anyone became disabled, and needed a large amount of support, they didn't have to go broke, which is what happened before the NDIS. And, you know, we said this a lot at the time. And I feel like we have to keep saying it again, that if you got hit by a car, and you had a particular injury, and needed a whole lot of support, you probably got that support before the NDIS. If you fell off a ladder and had the exact same injury, and the exact same support needs, you got nothing. And your family literally had to mortgage their house.

**El**

Or if they didn't have that money, you literally got no support. And you would go and live in aged care. And I feel like people have forgotten what happened beforehand, and the lives of disabled people that we need to build in this new system. So I wanted to remind people that this was about sharing those costs, like we do with lots of things. Like we don't expect people to, you know, if you get very, very sick in Australia, thank god, and you have the kind of illness that our hospital system can treat, you are treated, and you are not expected to go bankrupt for that treatment. You know, like you do in America, or in other places with health systems where the costs aren’t cheap. And I know as well as anyone that that is not uh, our health system doesn't work for lots of people, particularly people with chronic illness. And that is a problem that we are still yet to fix.

**El**

But the NDIS was meant to share those costs, because it is expensive. And if you need 24/7 care and support, that is expensive. And your family and yourself shouldn't be expected to carry that by itself. We share those costs. That's what we do. So I wanted to remind people around that, and try to get people to understand that to make the NDIS work, we all have to be invested in its’ success. And for those of us on the left and progressive side of politics - I want the profiteers out. I want them out. I want there to be no profit. You should not be able to make profit from care, in my opinion.

**El**

And while we have public money going to prop up shareholders, we cannot have a decent conversation about the costs of the NDIS. But I also think we also need to look at things like the very large service providers that have gotten very large. The biggest one, Life Without Barriers, is close to nearly $800 million revenue a year. That is an enormous organisation. And we have to think about what it means when we have these enormous organisations that are now not necessarily with as much oversight as we want.

**El**

So they're the conversations that I want to have around how the NDIS works and how much it costs. And that, you know, at the end of the day, maybe it just does cost a shitload. And that's okay. Like I really just- it makes me- (sighing) yeah. I just- disabled people are worth every bloody penny, you know? Disabled people are the best people I know. So I'm okay with spending money on the supports that we need. And I want all of us to have the supports we need and not to have to fight so hard. So I think a system where we are okay about spending that money has to be okay. It has to be the system that we fight for.

**Pauline**

El I was wondering what you think the likely role of non-disabled led organisations (so for example for-profit organisations, not-for-profit providers, unions and other non-disabled people), will take in the review?

**El**

Yeah, I think it's a good really good question. It probably won't be a surprise to you that I have real concerns about where our national disability organisations are at and their capacity to participate in the review. Every Australian Counts is very small. It's one person (laughing), and can't be expected to coordinate an entire sector of disabled people to have their say. I'm very worried about who is going to get heard during this review. And, you know, the people who should be getting heard to start with are people with intellectual disability, particularly say people who live in group homes. So I mean, what should they be doing?

**El**

I mean, I can think of two organisations, one in Victoria (VALID), and one in New South Wales. So CDAH in Newcastle and Hunter. They both do peer led work with people with intellectual disability who go into group homes in their areas to find out what's going on. And they talk to people who live there, they take the time to get to know each other, they work out problems, they get them the support they need. Why don't they work with those kinds of organisations doing that work? Give them money, give them a lot of money to go and do more of that so that their voices are the first that you hear about.

**El**

But what I think is going to happen is that the big organisations, particularly the big for-profit ones, that are all listed on the stock market, being all fancy, are going to hire expensive lobbying firms, and run big media and fundraising campaigns, with politicians and all of that stuff. And they'll get their voices heard, and what they want is what's going to come out of it. So I think I worry a lot about who has power in the NDIS and who doesn't. Who is going to get heard and listened to, as we build a system that gives people with the least a chance at an ordinary life. A chance to live in the community and to go to work and to hang out with their friends and go to the pub and have a family, you know, ordinary stuff.

**Pauline**

What are the stakes for disabled people if the review results in a reduction of funding?

**El**

Yeah, I think I think there are a couple of things at stake, I think the individualised plans are at stake. I think that is a huge risk. I think other things are on the table, like people only being able to use registered providers. So one of the things that I've said recently, in my Patreon writings, has been what I called ‘the microwave rule’.

The NDIS, over the last couple of years has tried very hard to, because everyone's freaking out about money, right? They've tried very hard to differentiate what is an NDIS cost, and then what belongs somewhere else. So what should be the health cost or an education cost, or a mainstream cost or an everyday expense, or however else they do it, they've got this whole website called “what we will fund”. What that's ended up meaning is that for disabled people, remember, half of us live in poverty, right? So we're relying on income support payments.

**El**

For disabled people, there sometimes is really perverse decisions made. So the microwave rule is, so say, for a disabled person, who if they got a microwave, they could reheat dinners from the freezer, and that would keep them, they would be independent. And that would be a really good thing that they could do, right? They could buy things from supermarket, that will be fine, they can afford that. Or friends could drop over some frozen food and they can heat it up the microwave. And that would be a way for them to be independent, and to be able to manage for themselves. But they can't afford a $300 microwave. The NDIS won't pay for a $300 microwave, but the NDIS will pay for a support worker to go in three times a day and cook that person a meal. Right? Whether that person can afford to buy food or not. And I think those kind of weird, perverse incentives have to change.

**El**

For the NDIS to work, the NDIS and the government have to trust disabled people. They have to trust us and our families, that disabled people know best about spending that money. The more oversight and layers of checking and whatever else they do, that they put on there - the more the costs will grow. And instead of trusting disabled people with the funds that they have, that they know best and that they will do best, with supports to actually figure out that and to learn how to do that, peer support, all sorts of you know, innovative ideas.

**El**

I just worry that none of that is even on the table. And instead we're just gonna get more complexity. More layers of people to explain how that complexity works, and less and less actual community inclusion, which is what the NDIS was meant to do. But instead you get support workers rather than a microwave. You get exercise physiologists rather than a pass the pool. You work in an ADE like a sheltered workshop rather than at Bunnings. And you live in a group home rather than with your mates in a house. And I worry so much that that's what's expensive - this separate system. And now there are a lot of people whose jobs depend on this separate system, and they're not disabled people.

**Pauline**

We all feel a massive fight coming with this NDIS review, what must disabled people do to protect our NDIS and forced the actual changes that we collectively need?

**El**

So I think you should put an ask on your organisations. So if you have a peak organisation that represents you, write to them. Ring them up. Email them. What are you doing about the review? What is your plan? There are people paid to do disability advocacy work. I would first of all, put an ask on them. So there are state and territory peak organisations and their national peak organisations. So make an ask, ring them up, send them an email.

Ask them on social media. I think get together with some friends. And you know, have a think about, what's the one or two most important things that you want to say? Like it can be really overwhelming to think “oh my god, I've got to fix all the things about the NDIS”. But pick one or two things, and write to the review about that. And do it in however way you want to do.

**El**

It doesn't have to be fancy. It doesn't have to be detailed. Just write to the review. They’ve got the details on their website about the consultation. It's not as much an easy read as I would like. But yeah, get involved. Follow Every Australian Counts on social media, because they will keep everybody updated about all the different things that are going to happen. And if you're in a union, ask them if they are going to support - particularly one of the unions involved in the NDIS (looking at you HACSU). Ask them if they support the individualised funding and if they don't then get organised with your workmates around pushing back on that stuff, because there are unions that are pushing to go back to block funding. And that would be a disaster, an absolute disaster.

**El**

Just on that, with block funding, there is one exception to that. First People’s Disability Network has made an ask about block funding for remote areas, but it is to be community controlled. And I think whatever First People’s Disability Network says, they've been arguing for that for a long time. And I think they're right. Because I think for remote areas, things are different in terms of, there is no infrastructure and no support.

And there are predatory providers going out there at the moment. So community controlled organisations fit with broader reforms that FPDN is asking for. So that would be my only exception around block funding. And there are a couple of others that people have talked about. But again, they are peer run, they are disability lead and disability run. They're not for profit, or even not for profit providers, setting all the rules.

**Pauline**

Moving on to my final question. The theme this year for the Disability Day broadcast is Rest Is Survival. And it has really come out of so many conversations I've had this year with economically marginalised disabled people in my networks, struggling to deal with the ramifications of being abandoned by the state, by the broader population, when it came to COVID public health measures.

**Pauline**

In addition to just about every other thing our community has to deal with on the daily, so many are burnt out. So many disabled people are unable to access rest. I myself was able to take deep rest for my body this year after it shut down at the beginning of the year. But I'm very aware I was only able to take that rest because I have stable housing and access to the DSP, which many disabled people do not. So I wanted to know about your experiences El, of rest throughout the pandemic.

**El**

I'll try and get through it without crying. It's a really important question, Pauline, and I'm so grateful that you've had this year. That makes me really happy that you've had this time. I'm back in isolation again. I'm one of those people who is immunosuppressed and I have other stuff that if I got COVID, it would be a disaster. There's COVID everywhere around me at the moment, I had a brief moment out to come down to Melbourne to see my mum and done one other trip and then that's it.

**El**

I have spent most of this year here by myself. And I have been thinking a lot about this, about how we make this work sustainable. When for so many of us, coming to the end of the third year of the pandemic, there's been a lot of grief, and a lot of sadness, and a lot of really confronting realisations about where we sit in the world. That for a lot of our communities, we're not as included as we had hoped to be, or maybe thought we were. I wrote that essay, god, a year ago now. For Meanjin that was published earlier this year. And it was very hard to write. But I'm glad I did it.

**El**

Because I think it gets down on paper, the loneliness of a lot of this time. And I have filled a lot of that time with work. And my friends joked when I started the Patreon, went “Great Elle! You can now work seven days a week”. And they weren’t incorrect. So yeah, and I'm in another period of doing way too much at the moment. Yeah, I don't have answers to that. I think that a lot of the way that we do disability advocacy in Australia is really ableist and really alienating for disabled people. I think that most of the deadlines by government, and the way we practice, engagement and consultation and do all of that stuff are out of reach for most disabled people. And that makes it wrong, it makes it wrong. We get the wrong policies, and we get the wrong responses to things because we don't take the time to listen and to do the work to include disabled people. Now, most of our disability organisations are not run by disabled people anymore. Because the work is now so difficult and fast. And there's been no pushing back.

**El**

The pushing back has happened, but it's been a pushing out of us. Disabled people get pushed out of our own organisations, because we can't work that hard. We can't do the 60 hours a week. And I just- I'm really angry about it, I feel really pissed off that we haven't been able to build organisations that support disabled people to not break ourselves to do this work. And I know an awful lot of people who have now left and don't do that and are finding solace in other places. I'm one of them. I left the advocacy movement this year, really angry and really hurt. And, I’m to going swear, fucking exhausted. Our liberation can't come out of- too many of our disabled people have died through work. Overwork.

**El**

Lesley Hall was one of my heroes, and she died getting the NDIS over the line. It killed her that work. It killed her. And so many of us who are disabled leaders have died doing this work. And is that what we're expected to do? Well non-disabled people just think it's a job and they can work 50 hours a week, 60 hours a week. We can't. And so what does that mean, that we just shouldn't be in charge? No! It means we should do the work differently so that we can do this. And I think we need to have more discussions in Australia. What Leah Lakshmi Piepzna-Samarasinha talks about: doing it in our time and in our way.

**El**

You get better stuff from that. It's not because it's nice to have or whatever. It’s what I talk about with campaigning, you don't do it- like I'm doing this work with people with intellectual disability at the moment. And you know, we don't do consultation because it's nice to have, we do it because it's how we win. It’s how we get the right result. Because we listen to what people with intellectual disability say, and we do what they tell us to do. Like I'm doing work about employment with them. And the thing they've said to me that's most important, is getting paid more. Of course it is, you know?

**El**

But people run around and make all sorts of other assumptions about what's important. But they're like, “No, I just want more money. I get paid like shit. It's disrespectful, and I can't buy it. I can't do anything. I'm stuck with no money”. And so just, I think it's time for a change. It's time for change in our organisations that represent us and a change in the way that we're doing this work. Because this is not how we get justice for us, by killing each other, and being expected to work at such a pace that we have no time for joy and art and love and life and you know, hanging out and doing nothing.

**Pauline**

That was the incredible El Gibbs. Stay tuned for more Disability Day programming.

**Voiceover**

3CR: Here to stay.