# The Canberra Disability Review

People With Disabilities ACT Inc

Original writing and voices on disability for Canberra

Issue # 1 – Winter 2016

## The NDIS Cometh...

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## Acknowledgement of Country

We acknowledge the traditional custodians of this land, the Ngunnawal people. The PWD ACT offices, where we publish and distribute The Canberra Disability Review, is on the traditional land of these people.

Welcome to this first edition of *The Canberra Disability Review* – a new initiative for us here at People with Disabilities ACT.

We're a consumer voice for people with disabilities governed by people with disability here in Canberra.

PWD ACT has a long history of consumer lead publishing here in Canberra.

First through the DPI newsletter edited by Dennis Stabback, then the ambitious *Disability Reporter* which ran for ten editions between 1999 and 2005 followed by our information based newsletter called Out & About with Ability we've been keeping people in touch and informed.

Each of these was of its time but lately we've been seeing a need for lengthier analysis and reporting on disability issues here in Canberra.

Those of us who have been around for a while can remember the days when disability was hardly mentioned at all and was a parking lot for Territory and Federal Ministers of mixed quality.

These days disability is a $23 billion national investment scheme with its own COAG agreement and regular engagement in the 24 hour news cycle. There are major reform agenda's around in housing, employment services, "specialist" disability housing and Gonski. At the same time there are risks – especially at the Territory level, that disability may once again sink into obscurity in all bar specialist services.

I don't know about you but here at PWD ACT we get a million newsletters and alerts in the mailbox about disability issues.

Who has time to read them or to wade through it all and gain a deep understanding of the one issue? Are they adding to our understanding or are we just getting more lost?

For that reason we've opted to reimagine our newsletter into a journal we hope you'll want to keep on your shelves and web browsers for a while.

Our focus will be on original content including in-depth interviews, features, opinion editorial articles, reviews and essays from people with disabilities, policy makers and opinion leaders. We will be inviting people to submit and also considering unsolicited submissions. It will be your voice – not just ours.

The purpose of the journal is to: spark a greater level of critical thinking on disability issues; provide a space for long form essays, opinion pieces and feature articles; inform policy makers; and provide an advocacy platform which shows we are serious and is taken seriously by decision makers.

In this first edition we hear from Christina Ryan, the CEO of Advocacy for Inclusion in a fascinating interview which cuts to some problems in the implementation; Richard Baumgart from the NDIS Taskforce; Robert Altamore about wrangling with self management; and from Emillio Del Torres who writes a thought provoking think piece about the implications of a scheme centred on individual decision making in a cultural context that asks women to put everyone else's needs over their own. We also hear directly from NDIS participants wrangling with the portal.

And who says that disability can't look good or have a quality finish?

For that reason we've commissioned the fantastic Richard Tuffin and a great online designer to help us produce a journal that we hope is easy on the eye as well as being food for the mind.

The theme we gave Richard was two Canberra's – we want to show that there are two physical Canberra's and two ways of viewing Canberra – an accessible national capital precinct with affluence and another Canberra sometimes in view of the other, which can be inaccessible, unaffordable and unfriendly to aged and disabled people.

We hope you enjoy the results of it all ...

*Craig Wallace*
*Editor*

# Christina Ryan

## CEO of Advocacy for Inclusion speaks out on NDIS, human rights, advocacy and wrangling with the NDIS portal

**What should the 5000 Canberrans entering the NDIS expect from it?**

The big one up front is greater independence in a number of different ways. There's greater independence generally so people are able to just do more for themselves in their lives, but coupled with that is the greater independence that people have in their own life and their own space. That sense of who is actually making the decisions, who is actually the driving force. I think that's the biggest shift that we'd want to be looking to for people.

That will result in all those downstream economic effects that people want to see like greater employment, greater community engagement, greater economic engagement.

**In practical terms, what should people be doing now?**

Particularly in Canberra because we are at the point where almost everyone should have gone in, what people need to be doing now is taking advantage of whats come their way. There are people who still are needing support for that to happen and they need to be making sure they ask for it, speak up and are being supported.

There are also people who are waiting for services to be built or are not sure what they should be looking for – get out there and have a look.

I think the best thing that people with disabilities could be doing is simply getting out there and having a life. I think there is a really big theme that this isn't going to work unless we actually get out there and are more visible in the community.

**If someone is approaching a planning session right now what should they be doing?**

Prepare! Do not turn up to your planning session without quite a lot of preparation. People who go in cold are not having a good experience. It's really important people spend quite a period of time leading up to that planning session having a look at what they've got, whether that's what they want, whether they'd like to be setting some goals – they mightn't be life changing goals but you might have a goal to have an annual holiday that you've never done because you haven't been able to. You might have a goal to study something

that you are interested in studying. They can be goals that anybody might have but make sure you know what they are because that will form the core of your plan.

Use the templates. There are some good NDIS templates. Put some thinking in before you go to that planning meeting. Who are the people you can call on? Who are the natural supports if you have them? What are the things that are going well that you want to hang onto? What are the things you have always wanted to do or achieve that this plan will help you do?

Don't think about it as a shopping list. It's not about getting this gadget and that piece of equipment or the hours of support – it's actually about how you achieve your goals.

People sometimes think about goals as just being employment or education.

They might be different. They might be about retaining relationships. There might be goals about being unable to get out and socialise occasionally. They might be goals about becoming independent where you have previously had to rely on equipment to get you by. It might be about getting healthier and having a greater sense of wellbeing because you are able to engage in a greater range of activities than you have before.

Goals are specific to the person. They don't have to be big life changing goals around employment or having a degree in astrophysics! It might be, but it might also be very simple things that others take for granted.

**If you had to make an overall assessment of how happy people were and how they were going with plans, what would that be? Or is it too early to do that?**

I don't think its too early. The big statement that has to be made is that nobody who now has access to an NDIS plan would prefer that they didn't. There is a real shift in people thinking "this is where my life could be heading".

There's a truckload of things we have to fix. Glitches that need to be tweaked. That's part of the trial. But there is nobody saying "the system we had before is a preferable one" even people who are struggling really badly with the support not coming together yet know the amount of control they had is improved and the types of supports they can get are different from what they had before.

We're seeing glimmers of what a decade from now might become everyday expectations.

There's a lot we need to do to make processes more streamlined. There's an awful lot we need to do to get rid of the bureaucracy in the NDIS. If you want to build a bureaucracy they have done a very good job of building the most big and monolithic bureaucracy you could possibly manage. That has to be fixed.

But people are embracing plans in a way that is life changing. It really is.

**Do you think that because we have been in campaign mode that there has been a lack of critical analysis of how well this is rolling out?**

Yes and no. There has been a lot of things that have been happening without thinking and kneejerk reaction. But there has been a lot of thinking and analysis. The national evaluation process which Advocacy for Inclusion is part of in the ACT has had a helicopter view of what's happening.

I don't know that its broad enough to cover everything, but the evidence of how peoples lives have shifted has been coming through.

I think the NDIA has been very good at listening to people on the front line – both people with disabilities and the people who represent them have been treated with respect when they say the system isn't quite there.

What we've got though is a bunch of people without disabilities who have no idea of what its like to live with a fair degree of support needs putting in place systems that don't work for those people. There is still some fear from the people behind the scenes designing it all about people with disabilities running their own lives. It's not the planners but the people behind the scenes such as people in Social Services who aren't engaged in the front line

**What's the bureaucracy like in self management?**

Six years ago, when we started building and designing, we wanted the NDIS to be flexible so those of us who need support can identify what works and identify what suits us best. We seem to have a bureaucracy that is a bit frightened of that. That's partly understandable – there is no other agency that has so much independence for people on the receiving end.

The process of eligibility is quite arduous. It can take months. The process of implementing your plan can also be quite arduous. The paperwork is actually significant for people. We're getting evidence that its so arduous that people are finding it impossible to self manage. In Canberra this is a very important thing because we have a very high proportion of self-management of plans in the ACT. As more people who are able to self manage become plan recipients we need to ensure we have systems in place so that we are actually supporting them to live their life rather than expecting them to prove the exact amounts they spend everyday on an activity.

**There's an awful lot we need to do to get rid of the bureaucracy in the NDIS**

We have to keep a close eye on this. We have to be really careful of how much they are putting in place that might look ok from a bureaucratic view but from the point of view of an individual person with disability makes life harder. We want to put our energy into living.

The rest of the world doesn't know what it takes to live our lives or just how much we have to put into our disability every day. It's not just organising – it's the

sheer fatigue of having a disability and operating. People are always tired.

**Are people who are self managing having to absorb too much of the administrative and financial burden?**

Yes. I think they are and the scheme is going to have to get on top of this quickly. If it doesn't we're just going to end up with the old scheme with more money and more resources – it's exactly what the Productivity Commission identified that we don't want.

If we don't get on top of this now we are simply recreating the old system in bigger form. That's not what anybody wanted and its certainly not what was intended when we started designing this six years ago. It must restore flexibility and simplicity for individuals. It needs to be as simple as paying electricity or a doctors bill.

One of the kneejerk things that they have done is payment in arrears. Originally the scheme was designed that you got your money upfront. Either all or some of it. They put in place mandatory requirements like having a separate bank account to put your money into and they had a very simple template for aquittals. What they've done in a kneejerk reaction to people struggling with that system is to completely remove it and now have a system based solely on reimbursement which means you have to spend the money before you can apply through a very complex bureaucratic process to have the money repaid to you. Clearly this isn't what we originally expected. If people had the money to pay for their supports they'd be doing that already. It's mainly an issue with day to day supports rather than big expensive pieces of equipment which go through the NDIS anyway.

There is a very large burden of proof and a very heavy overuse of occupational therapists. A very high level of demand by the NDIA that people prove that a piece of equipment is the one that they need, which for people who've been using equipment for decades is a very large overlay of bureaucracy. We know what we need and we know what the best options are. Having to go through a full OT assessment process every time is a bit much. If you spend 6 or 12 months waiting for an OT assessment so you can get a new wheelchair may as well go back to the old system.

People have been waiting months for OT assessments for large pieces of equipment or house modifications. Any of these also need to go to a special committee for approval if the cost is over a certain amount and that process can take some months as well. You don't just get the OT report you've then got to wait for the committee to approve whats being done. From go to woe it can take a long time.

**Is there a problem with OTs?**

There is a shortage of decent OT's in Canberra or any OT's. But a lot of the delays are about gatekeeping and requirements for proof and more proof. Even when you have an OT report that says "this is the right piece of equipment" – they will come back and say well we bought this for someone else and it cost less so why cant you have

the other one. Things like that just shouldn't be happening. Every person is unique. Every person has things that work best for them.

Some OT's still work from a medical model of disability – about fixing you rather than removing barriers. The other problem is people being left out of their own processes so they are not even consulted by these so called experts on what the best solution is. There is an assumption we can never be the experts. That's got to change and I think the NDIS will change over time as it gets better, over the next decade or two.

**How well do you think the transition arrangements between the Territory Government and the Commonwealth Government are being handled?**

It's a bit slapdash. The fact that the ACT went in early and went in full is fantastic. It was such as big relief to so many people with disabilities. Five years ago everyone was exhausted and at the end of their tether and that commitment by the ACT Government that this just has to happen was such a relief and changed peoples mindset.

The big problem that we've had is that just about the entire funding commitment for the NDIS arriving in the ACT has been thrown at service providers. Very little support and preparation has been devoted to people with disability and this really only happened over the last 18 months or so after the scheme started rolling out.

People who have significant cognitive or communications barriers and those whodon't go to things like seminars were given almost no opportunity to prepare. Most of those people were given no planning preparation or chance to identify what the NDIS could do for them. Or how to prepare. Or how to take control. There was a lack of commitment to funding that preparatory work. Just this morning I saw an email about some activities happening in NSW as they move to rolling out and there was a signifaicant commitment of millions of dollars to reach people with disabilities and I thought if we had even a bit of that this would have been a very different conversation. Rather than prepare people with disabilities in the ACT the scheme has almost been thrust upon them.

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*This interview was recorded on 31 May 2016*

# Richard Baumgart

## Executive Director of Disability and Therapy ACT in the ACT Government was interviewed by email for *The Canberra Disability Review* on the rollout

**What is your role?**

The ACT NDIS Taskforce began in December 2012 to support the ACT to get ready for, and then transition to, the scheme. As the Executive Director of Disability and Therapy ACT, my role is to lead this work and the delivery and wind up of Disability ACT and Therapy ACT services.

This means working closely with our colleagues in the National Disability Insurance Agency (NDIA) and the Department of Social Services which manages the National Disability Insurance Scheme (NDIS) funding. It is about ensuring that the transition is understood, supported by and coordinated with, the work of other ACT Government directorates in particular Health, Education and Treasury.

One of the most important parts of my role is ensuring people with disability and service providers are kept abreast of what is happening and how they can ensure the NDIS works for them. There is so much change occurring that it can be difficult to identify what it means for an individual or an organisation.

**For people who don't know can you give us a brief overview of how the transition is being organised in the ACT?**

The ACT was one of the first jurisdictions to sign up to the NDIS and will be the first State or Territory to accept all eligible people into the scheme. The ACT's NDIS two-year trial began in July 2014. In the ACT we have developed a model where residents transition into the NDIS by age and life stage. For example the first people to go into the scheme were those aged 64 – to ensure they did not miss the age cut-off – and children under two years. People living in supported accommodation transitioned at the same time but under a different age arrangement. More detail about this is on our website: *http://tinyurl.com/zjfa4ju*

By September 2016 we expect that all eligible ACT residents will be connected to the scheme.

One of the first things we needed to sort out before we could figure out how to move disability services and service users to the NDIS was to understand what specialist disability services should do and what we should be expecting mainstreams services do, as part of reasonable adjustment or accommodation, to enable people with disabilities to access their services.

This was tricky especially as the scheme design was not finalised at that time, but I believe that we got this right.

**What are some key challenges in the transition from the point of view of the ACT Government?**

An important principle of the NDIS is that people can choose who provides their supports and services. Historically, the ACT has not seen much by way of new service types and new providers coming in because government has held so much of the market. The ACT Government decided to gradually move out of providing disability services by June 2017 to enable the community sector (or market) to grow. This has obviously been a big change and challenge for service users and their families, as well as to

our own staff and the community sector. Considering the scale of this change, it has gone well. Currently, more than 200 organisations have registered with the NDIA to provide services in the ACT. The ACT and Commonwealth Governments are investing $21.8 million to prepare the ACT sector and people with disability for the NDIS.

Another challenge has been in making sure that enough and the right mix of NDIS preparation information and assistance is available to people with disability and their families and to the funded service providers that have been working with them. We have distributed information in lots of different ways but we know there are still people who don't know what the NDIS is or don't know if they should be applying. That is a concern and something we continue to work on with the NDIA.

As people increasingly exercise choice over the services they want in their homes and lives; and as people choose to manage their funding, we are going to see a very different looking market of options being available to them in Canberra. I think that will be a good outcome for our community. We will also see people with disabilities and their families being able to take part in training and employment and trainings.

**What should people with disability and families being doing now to be ready?**

I think it's really important that people start to think about the things that make a good life for them, what they want to achieve or do differently and then to think about what sorts of assistance do they need to achieve that. The ACT Government has also funded a program called "Your Voice Your Choice" to assist to people to get ready for the NDIS. This program is particularly looking to work with people who are finding it most tricky. Your Voice Your Choice can be contacted on 6246 7100 and more information is on our website: *http://tinyurl.com/zpvj9fu*

**For the first time ever all people who need support will be able to get the support they need**

The social and system impact of the introduction of the NDIS can't be understated. It's been a massive change for our providers who have been funded by government contracts for many years and now need to move to a new fee for service environment. An environment in which their usual service users decide they want to get their services from another provider.

**Do you have any messages for people with disability or service providers who might be nervous about their futures?**

The NDIS presents huge opportunities for people with disability because for the first time ever all people who need support will be able to get the support they need. But it is a totally different way of getting supports and for service providers it's a completely new way of being funded.

We know from NDIA reports that people with disability are overwhelmingly satisfied with their new arrangements and many are receiving supports they have never had access to before.

Various NDIA reports are at: *http://tinyurl.com/hae3ak9*

Naturally some people are nervous about the changes. It's also inevitable, in moving to a whole new and developing national scheme, that there will be bumps along the way. We know some people have difficulties getting their access to the scheme sorted, people have experienced delays in developing plans and then figuring out what to do when they have a plan.

It's important that we are patient through the teething problems but also that we raise issues as they come up. We all need to make sure the scheme continues to develop in the right way so it can really deliver on the principles of choices and control for all Australians for generations to come.

People with disability will have a lifelong relationship with the NDIA so the first plan isn't the last, there will be many plans and support packages. People will be able to adjust the range and types of supports they get as their circumstance change.

**Are you concerned that there are services – like TADACT or other ILC services that are falling between the cracks?**

The NDIS includes the range of services that provide Information, Linkages and Capacity Building (ILC). These services support people in different ways, to take part in their community. ILC services might assist people with disabilities and their families to build the skills, resources and confidence they need to participate in the community or to access the same kind of programs and services as other people.

We are working with the NDIA around the implementation of the Information, Linkages and Capacity Building component of the NDIS. The ACT Government is committed to a viable ILC system that works with mainstream services and the broader human service system to meet the needs of the ACT community.

These services have been given an additional 12 months funding so they have time to either change their service model to be able to be funded through people's NDIS packages or to get ready to apply to a tender which will be run by the NDIA to block fund ILC services for the ACT from 2017.

Since 2014 the ACT had access to $12 million Commonwealth NDIS Sector Development Funding so there have been a range of resources available to help our community providers to get ready for the NDIS.

ACT providers that have been impacted by the changes to the ILC type services were given priority consider-

ation for the 2016 ACT NDIS Business Investment Packages. These grants valued at up to $50,000 per organisation enabled providers to buy in the tailored development assistance they need.

Also Ready4 provides a first point of information about all of the service development resources available and directly provide a host of targeted and professional assistance themselves:
*http://tinyurl.com/hw6nt35*

**In other jurisdictions like NSW we are hearing about the State Governments pulling out of disability entirely. Is there still a role for disability policy in the ACT and what are you able to tell us about how that is shaping up?**

The ACT Government remains committed to ensuring that people with disability are fully participating citizens in the ACT. This means that we have a strong commitment to the National Disability Strategy and will continue to play a role in its implementation. The Community Services Directorate is still shaping this new arrangement and it will be finalised in the coming months.

**This is a big transition for Disability ACT staff and your people – how is that side of it going?**

Yes the transition from service provision has been a big job.

Disability ACT set up a People Management Team to support staff through the transition. Information sessions, fact sheets, close union engagement and a case management approach have been used to support our people to consider, choose and then move to their preferred options.

It's going extremely well and I have been surprised by the diverse directions our people have been taking. Importantly many, almost 200 permanent staff, are staying in the field and have been employed by community providers. This is an amazing outcome, providing consistency in support for clients we have known for so many years and keeping highly qualified and experienced staff in the sector. Excitingly staff, including therapists, have also set up their own NDIS businesses.

Disability ACT set up a Change, Transition and Transformation Team to oversee the transition of clients to the NDIS. This is progressing rapidly. As of 26 May 2016 117 clients who live in 40 households had transitioned to the NDIS and their preferred new provider. Again this is going well and we have had many positive messages back for the families of people we have supported about their satisfaction with the transition and the new arrangements.

**Would you like to make any observations about the way Commonwealth/Territory relations are playing out in the rollout? Is the ACT getting the information and the cooperation it needs to deliver its obligations?**

The ACT Government has a good relationship with the NDIA at the national and local levels. We have been working together effectively to implement this major social change. The ACT NDIA has been responsive to issues as we have raised them so I'm confident that we will continue to work together through the roll out the ILC services and move the ACT in a state of full scheme.

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*The Canberra Disability Review made repeated attempts to secure an interview with the ACT NDIA trial site manager Jim Callow but didn't receive a response by deadline.*

LISTEN

# Vox Populi *(n) "the voice of the people." (L)*

### Lina:

"I have several issues with the portal.

1) Quite a few times I have logged on to do my payments and it has been down for what ever reason. And it might be some time before I have time to sit down and try again...

2) I'm not a natural accounts keeper so I was carefully doing each claim separately, so I could keep track of the payments into my bank account...but they don't come across as separate deposits as I wanted but as one big lump – so during the lag between making my claim and getting the funds (and getting back on line) I lose track.

3) I would like to be able to write notes on my portal records so I can easily keep detailed notes on what the payments were for, etc, etc...

4) One last gripe – (not directly related to the portal) – the very lengthy delays in receiving tax invoices from my service providers..."

### Maya:

"Despite all the hype, my family's experience of NDIS has been really positive. I had support coordination to assist me through the process which has been invaluable. My support coordinator gave me the advice and assistance I needed at every step to choose services and then later to use the portal. I decided to self-fund fewer lines this year and for NDIA to manage as many as possible. This helped me to manage the process a bit more efficiently. It has been a massive process to go through but the end result continues to be positive. NDIS has helped our family to access services and purchase equipment that we would never before have been able to afford."

LEARN

# The Facts on NDIS in the ACT

### The basic facts:

Eligibility isn't, generally, about the type of disability you have, its what it does, is it permanent and does it effect you in your daily life

NDIS covers reasonable and necessary supports you need due to your disability

NDIS covers supports most appropriately provided through the NDIS and not through another system like health or education.

### What you need to know and do:

In the ACT, people are accessing the Scheme based on an 'ages and stages' approach. This means that people with disability enter the NDIS according to either their date of birth or, for school-age children, their academic year.

People in group homes will transition into the Scheme over a two-year period. When one person in a group home accesses the Scheme, so will all the other residents in that home.

**NDIS does not happen automatically** – you must fill in the Access Request Form from the NDIA and be assessed for access.

If you don't have a medical access form – for instance it's been lost in the post you should contact NDIS on 1800 800 110 or visit the NDIS at one its three ACT offices (9am to 5pm on weekdays) at 212 Northbourne Avenue, Braddon; Nature Conservation House, cnr Emu Bank and Benjamin Way, Belconnen; or 2-6 Bowes St, Woden (sharing with DHS)

If you haven't been able to get help in the past you might still be eligible for NDIS. You can use My Access Checker on the website to see if you may be able to access support from the Scheme. If you think you may be able to access supports under the NDIS, then you will need to complete the Access Request Form.

If you are using an existing service this does not automatically mean you will continue to receive it and get NDIS. You must get your Access Request Form in before the end of June or you risk gaps in your service.

Before meeting with a planner you need to prepare. You need to think about all the items you use and costs you incur. One thing that people find helpful is to keep a diary of the disability supports and equipment you use in a typical day.

# My DIY NDIS

## by Robert Altamore, Executive Officer of People With Disabilities ACT

When my turn came to transition to the NDIS, I thought I would do it myself. I am not a person that does DIY projects around the home but I thought this was a DIY that I could manage. After 9 months my verdict is that I am managing but not very well. So here in brief is my DIY NDIS journey.

The first thing I have noticed is the difficulties in accessing the forms. I would have thought that the forms would be easier to fill out on line and simpler. I have needed sighted help, including help from NDIS staff, to complete most of the forms. In particular the documentation you are meant to fill out prior to your planning meeting to record your goals and your support needs was not available to me in an accessible form. I had to write the answers to the questions out as a word document and give it to my planner to enter into the form.

The process for establishing my eligibility including my disability and my age and residence was easy for me but I think it could be unduly complex for many people. My GP commented that the medical form seemed unduly complex. When I filled it out it was 9 pages. I understand it is now 7 pages.

My Planning meeting went well. My Planner was new to disability. That didn't worry me as a person with a lifetime of knowledge and experience of my disability, what I needed and the available services. However, I fear for those who do not have these advantages.

The first unexpected surprise I got is when I took my Plan to my service providers. I was informed that my planner had put the wrong budget code numbers on my Plan and that because the Codes were wrong, I could not make claims for payment for services which I had received and paid for. I was able to fix this problem quickly but again I am sure this was due to my knowledge of knowing what to do and who to talk to. I believe a person without these advantages would have had much more difficulty in resolving this problem.

I also discovered that I had left one of my personal care needs off my plan. Again, the amount was small and I was able to quickly get my Plan amended to include this support.

For me the biggest problem with self-managing is the actual making of claims. You have to lodge claims and manage your funds through the MYGOV portal. The process is so clunky and difficult that it is hard to lodge a claim even with a sighted person sitting next to you helping you. The difficulty in lodging claims and in managing the money with the accuracy I would want to is a major problem in implementing your Plan.

I have heard that many people have given up on self-management and handed the management of their Plans to service providers. If I had to give up self management I would feel defeated and would feel that the NDIS had not given me the promised choice and control I long for.

My tips for when you are reviewing your plan or making your first plan. Is to keep a diary of your activities, what you do and the supports you need to do it. Also, when thinking of your future goals also think about the supports you will need. That way you won't leave things out.

My verdict on self-management is that if you feel you can self-manage do so. However, remember that self-management is stressful and requires skills in self-management and computer technology. My DIY NDIS is very much a work in progress.

# Sex and Destiny: It's Not a Mystery

## – says Emilia Della Torre in this think piece for *The Canberra Disability Review*

Now is a good time to stop and look at how the NDIS is rolling out in the ACT through a gender lens.

Some women with disabilities have become NDIS participants – but not all women with disabilities who are eligible have in fact become NDIS participants. We have gone to the pre-planning forums and workshops; filled out all the forms; applied to the NDIA and met with our planners; linked up our doctors and other providers; and developed our personal NDIS plan. In some cases we have asked for a review of specific decisions. Our NDIS plan is targeted to meet our individual needs in a way that marks a positive revolution in the way we are seen and supported. And yet overall, women with disabilities in the ACT have a thirty percent lower than expected uptake of the NDIS generally[1]. Why is this?

### Self-Censorship

*"...There are so many other people who need it [NDIS] more than me. I mean, I am pretty OK really. Other people need it more. I don't really have a disability."* [2]

The forces organising women's lives and the symbols, discourses and practices through which womanhood becomes meaningful in a variety of cultural contexts include notions of the self-sacrificing female who

1 Only approximately one third of NDIS participants in the ACT are women. Alice Tibbits, Director Engagement and Funding, NDIA Disability sector Quarterly Forum, Canberra (24 March 2016). Yet there are about 31,700 women with disabilities in the ACT, making up the majority (55.5%) of people with disabilities in the ACT. Australian Bureau of Statistics (2013), Survey of Disability, Ageing and Carers 2012, Cat.No. 4430.0, Table 5.1

2 Penny (not her real name), a young women with osteoarthritis. Interview with the author, 24 March 2016.

puts the needs of others ahead of her own equally legitimate needs.

"Towards the end of the interview the researcher asked Maria [a carer for her sister] if she would ever consider going through the process again in regards to her own situation. *Not really, she [the NDIA Planner] said have you ever thought about going on [the NDIS] and I'm like look, I don't know. In the end I decided I didn't want to because my needs weren't that great, or not as great as – I don't know, that's honestly how I saw it."* [1]

## The Confidence Gap

Research on gender stereotypes provides a powerful explanation for women's lower NDIS participation. Women continue to participate substantially less than men and receive a comparatively smaller proportion of funding allocations. A new book, *The Confidence Code (www.theconfidencecode.com)*, would largely attribute this to women's lower confidence when compared to men. Women are less likely to self-promote.[2]

*"... he says you're up to so much money and I say well what am I supposed to do? I mean am I entitled to these things [transport], am I not entitled to these things? I don't know, are they just going to go bang, bang and cut them halfway?"* [3]

*"I didn't ask for funding to see my acupuncturist as often as my acupuncturist recommended which is the recommended medical protocol. I just felt that it was too much money. They would think I was being greedy. So I asked for acupuncture treatments once a week. That's actually half of the recommended treatment, but ... "*

**Research on gender stereotypes provides a powerful explanation for women's lower NDIS participation**

## Rational and Relational Thinking

Like all women, women with disabilities are socialised to value relationships: to see the whole person and nurture relationships between individuals. The NDIS moves public policy in the direction of relational thinking by adopting a social model of disability. But the NDIS is a public program that contains inherent tensions. This is clearest in the types of therapies that are readily funded by the NDIS because they are considered to be evidence-based: physiotherapy rather than massage therapy; chemotherapy rather than Traditional Chinese Medicine. Women are the predominant users of complementary therapies[4] precisely because complementary therapies treat the whole person and not just a symptom.

*"I spoke about doing the mindfulness course, he (the NDIA staff member) said he's not sure if this could be funded under the NDIS and I would need empirical evidence."* [5]

Could this be a stumbling block for women with disabilities once we enter the NDIS system? It seems the answer to this question in the trial phase of the ACT roll-out is "Maybe". Of course, these are the very issues a trial should be established to test and fix. If NDIA guidelines do not contain any reference to gender-based considerations, if individual staffers are not aware of gender-based societal influences on women's and men's decision making, the current unequal allocation of resources will be perpetuated in the new system.

## Conclusion

*"The NDIS is a very new and complex scheme with highly positive and life changing outcomes on offer. There is no doubt the job of the NDIA is challenging and enormous, impossible to avoid teething problems and initial bumps."* [6]

There are genuine strategic opportunities for the NDIS to further integrate a gendered sensibility into its policies, practices and procedures. We can be proud of the fact the ACT was the only jurisdiction in Australia to engage a Gender Adviser in the initial phase of the NDIS roll out. Women With Disabilities ACT is currently scheduled to follow-up its initial consultations with women with disabilities to further explore our NDIS experiences. We are now at the exciting next step in this on-going NDIS development.

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*Emilia DELLA TORRE is the Principal Policy Officer for Women With Disabilities ACT (WWDACT). The views in this article benefit from the research undertaken by WWDACT but are her own opinions.*

1 Margie Women's experiences with the NDIA WWDACT 2015 at page 17. For privacy reasons real names were not used in this report.
2 For Women To Rise We Must Close 'The Confidence Gap' – Forbes (http://www.forbes.com/sites/margiewarrell/2016/01/20/gender-confidence-gap/) Jan 20, 2016
3 ibid at page 29
4 F. L. Bishop and G. T. Lewith, "Who uses CAM? A narrative review of demographic characteristics and health factors associated with CAM use," Evidence-based Complementary and Alternative Medicine, vol. 7, no. 1, pp. 11–28, 2010. A 2010 review of surveys investigating CAM use among community-based adults indicated an association between CAM use and gender, with women more likely than men to use CAM. This corroborates the findings of previous National Health Interview Survey (NHIS) reports.
5 Margie Women's experiences with the NDIA WWDACT 2015 at page 29
6 Women's experiences with the NDIA WWDACT 2015 at page 25

# NDIA Must Return Us To The Centre

In this first edition of *The Canberra Disability Review* we have chosen to focus a sharp lens on the rollout of the National Disability Insurance Scheme (NDIS) in the ACT. It is the single biggest administrative, support and service change in the lives of people with disability in living memory.

Over the past 5 years the disability rights community has been focused on ensuring that an NDIS happens at all, especially here in Canberra where we are an early adopter of the scheme and a crucible for the lobbying up on the hill.

This is understandable as we've faced a Federal Government that has sent out mixed signals about its real commitment to the scheme as often as its changed leaders.

However in the ACT the scheme is now well advanced and it's hard to see how Governments could reverse the bilateral arrangements at the heart of the scheme.

The question then becomes, not whether we have an NDIS at all, but whether we achieve the revolution of choice and control promised by the Productivity Commission or settle for a more muscular but chimerical reimagining of the old system.

Overwhelmingly the Scheme is making things better. People are experiencing unprecedented levels of support and are moving from survival mode into imagining a future beyond the next equipment failure or personal care shift. Where five years ago there was exhaustion and despair now there is hope

And yet there are things missing and hope is becoming tinged with frustration.

In her interview, Advocacy for Inclusion CEO Christina Ryan makes a compelling case that there is too much emphasis on service provider readiness and not enough on enabling consumers to imagine better and shape the scheme and their futures as their own.

We agree that the ACT should urgently prioritise efforts to build the capacity of consumers. It's time for our Ready4, especially for women who, as the compelling article from Emillia Del Torre argues, have a lower uptake than men and sometimes self-censor their needs. We need to see the colour of the money here and for the ACT's strong network of ILC services such as Radio for the Print Handicapped and TADACT.

There should be less bureaucracy, especially in self-management which is still alarmingly low right around Australia. The ACT has a tradition of partial self-managed support. If the NDIA can't get it right here, the chances of success anywhere seem grim.

Do It Yourself is always harder than it looks and as Robert Altamore makes clear the NDIS is no exception. The online portal needs to be revamped and we need to recognise that payment in arrears defeats the whole purpose of self-management. An anti-red tape agenda is needed here.

The rehabilitation industry – and that is what it is – also has its own bureaucracy and there should be less reliance on Occupational Therapists, especially for those consumers who are old hands at their own disability and know the kinds of equipment that works. A more cautious of OT's would be a wise move for the agency too, given the shortage of professionals in the ACT, the costs of consultancy services and the sure knowledge that people are experts in their own lives.

There has been much said about the "natural authority of families" yet the inbuilt authority that people with disabilities have about the most basic areas of our lives are often ignored. Usually when we say something won't work for us, we're right.

Finally the ACT NDIA needs a period of consolidation, consistency and consultation.

There have been too many changes in the local staffing and management of the Scheme in the ACT and the NDIA's support footprint needs to move beyond service providers and sway towards those the scheme was actually designed to help.

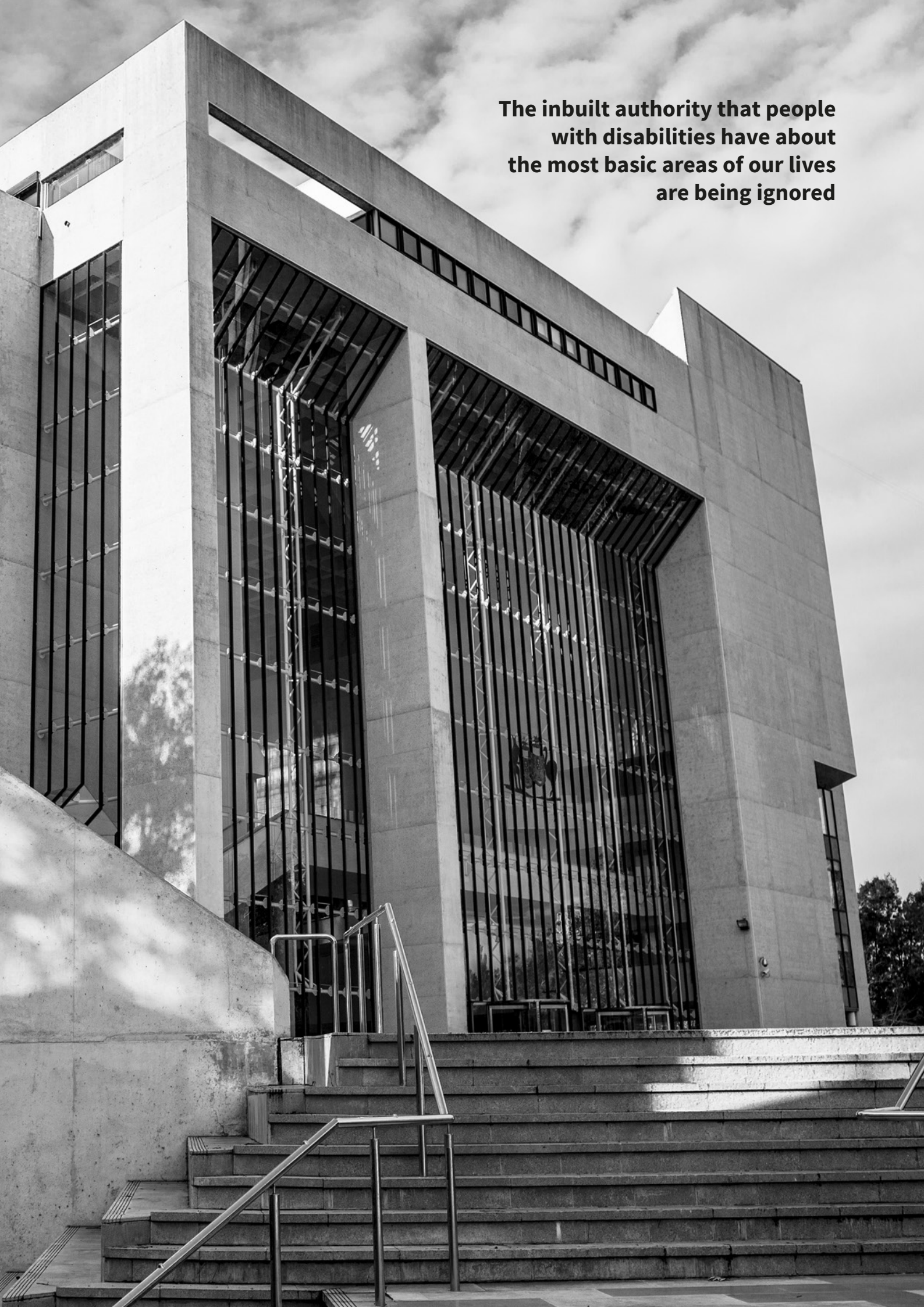
We were unable to talk to the manager of the NDIA for this edition of *The Canberra Disability Review*. We don't envy the pressures that must be falling on them right now. And yet to be effective it cannot become aloof or slave to process like other Australian Government service delivery agencies like Centrelink or DSS.

While there was much to improve within the Territories arrangements for disability, Disability ACT was a strong community partner and readily accessible to people with disability on the ground, knowing from long experience that the ACT disability rights community is organised and influential.

They have worked hard to engage people with disability and organisations as community partners.

As Richard Baumgart makes clear it's a tough transition for them so as they wind up we recognise the work they have done and hope that the spirit of engagement finds its way to the local NDIA.

We also hope the ACT Government steps up with its own program of work, including an office with identified positions, to drive disability policy work in justice, education, transport, employment and mainstream services.



**The inbuilt authority that people with disabilities have about the most basic areas of our lives are being ignored**

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