

LOOKING FORWARD, LOOKING BACK: STORIES FROM THE NDIS

People with
disability share
victories,
disappointments
and aspirations in
the tenth year of the
NDIS in the ACT



Women
With
Disabilities
Australia
(WWDA)



**An Advocacy for Inclusion publication from
the *NDIS Review Conversations Project*
conducted with the support of the Australian
Government through Women with Disabilities
Australia with assistance from Articulous.**



**Advocacy for Inclusion
acknowledges the Aboriginal
and Torres Strait Islander
peoples as traditional
custodians of the lands where
we live, learn, and work.**

ACKNOWLEDGEMENTS

Advocacy for Inclusion (AFI) acknowledges our principle contributors – Clare, Hazel, Nadia, Peter and Aanya. Your time, effort and commitment to truth telling made this what it is.

We acknowledge contributions from the AFI team – thanks Craig for developing this idea and Ros for stepping up and leading this project. We also acknowledge Carla for project support and Izzy as well.

A shout out to our individual advocates who manage and grapple with many of the NDIS issues you are about to read about every day. This is for you too.

We also thank our project partners in the NDIS review work, including Max Hardy Consulting and Jessie from Articulous. Max, you wrangled it perfectly, and Jessie you made it sing.

We acknowledge the funding support from the Australian Government through Women with Disabilities Australia. Thanks Carolyn for trusting us.

The images you see in *Looking Forward*, *Looking Back* were shot by Canberra photographer Andrew Sikorski with layout and design by Rob Donnelly Canberra Disability Review editor with the AFI team. Thank you for bringing our publication alive and giving voice to the stories here.

We also acknowledge the NDIA and its staff – these pages show we haven't got everything right but they also point to lives changed for the better. Thanks for engaging with us along the way.

A handwritten signature in black ink that reads "Nicolas". The signature is written in a cursive style with a horizontal line underneath the name.

Nicolas Lawler
Chief Executive Officer

LOOKING FORWARD, LOOKING BACK

MESSAGE FROM AFI

This is a moment of truth and clarity for disability services and the NDIS. And the paths ahead are full of wrong turns and traps.

Here in the ACT we are often a laboratory for change, and there is no clearer example of this than the National Disability Insurance Scheme (NDIS), where we were the first whole jurisdiction launch site identified for the scheme in 2013.



Most people with disability and carers welcomed a promised move towards additional funding and greater person-centred supports and none of us could be happy with the system we had. We were fed up with a broke and broken system applying triage to people with disability and families in desperate need of equipment, respite, communications support, domestic help and other basic disability supports.

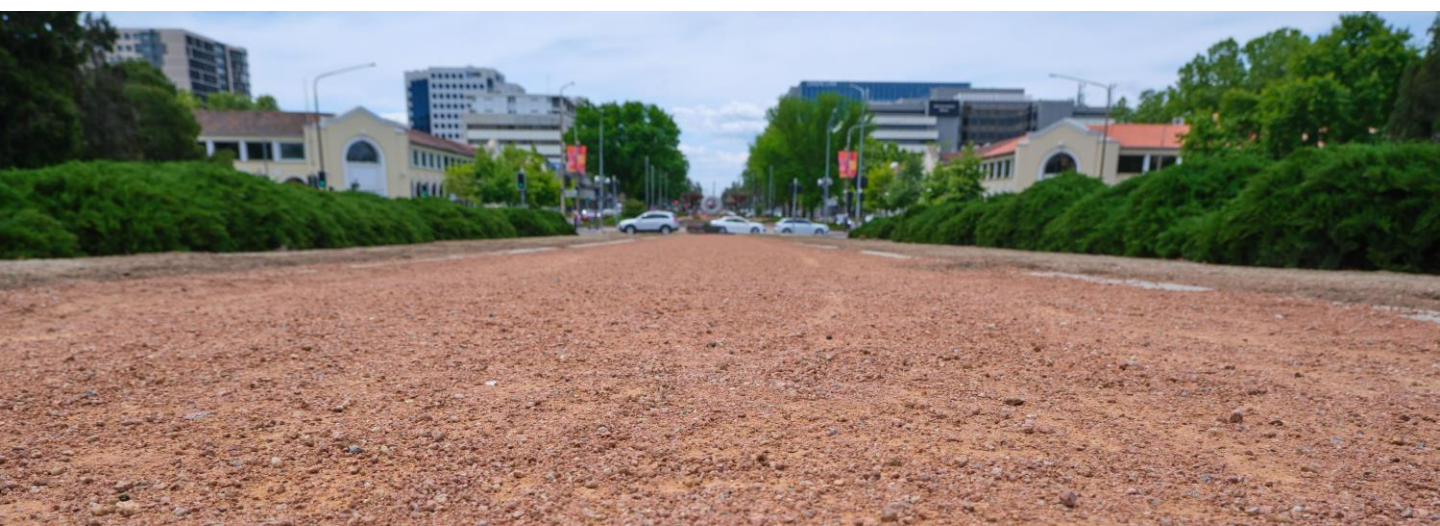
Change itself is not an enemy to good service provision, but it's also not an outcome on its own or a linear process, it can result in unintended outcomes and we are still only finding out what those impacts are.



No one sets out on a journey seeking to make people's lives worse but often when discussing change we spend all our time looking forward to the horizon, rather than watching the road just ahead and what the journey needs to look like on the way through.

Now the path ahead is unclear and full of doubt as the NDIS faces its most fundamental changes since inception. And by the time you read this publication we may well know much more about the shape of the NDIS review.

As change looms – along with the implementation of the findings from the Disability Royal Commission – it's worth reminding ourselves of the huge difference the NDIS has made while allowing ourselves a moment to acknowledge that some things have not gone as we might have hoped.



For that reason, AFI has been working across 2023 to give voice to ordinary people who can provide insight into how the NDIS is experienced. We worked closely and deeply with a small representative group of NDIS participants, chosen out of an Expression of Interest process, to capture and distil their NDIS experiences through depth interviews and an appreciative inquiry. A forum and a survey also gave us a chance to hear from a broader group.

The listening project was part of a consultation for the NDIS Review conducted on behalf of Women with Disabilities Australia with support of the Australian Government. Still, it also stems from work that we have been doing across the year to reflect on the ten years of the NDIS from the point of view of participants as it reaches its adolescence in the ACT, which was itself the launch site for the NDIS back in 2013.

Our NDIS review work informed a publications suite of which this is the third volume. Volume one, *the Appreciative Inquiry* speaks to building better communications with the NDIS. Volume two, *What We Heard*, covers the depth interviews. This third final volume gives voice to the participant stories in a relatable narrative form.

It's a review of how the scheme has been experienced but it also invites us to look forward to the next ten years.

In 2033 perhaps people will revisit these stories and look forward again to ponder the NDIS they want in 2043. For if there is one thing we all agree, it is that the NDIS is worth the journey.



When AFI started engagements around the NDIS, we were not sure there would be one, let alone *three* publications. But when we started hearing the stories of participants and the way they touched on varied but connecting themes it didn't take long for us to realise they deserved to find a broad audience in a valued setting.

We asked what has been lost and what has been gained. They invite us to ask whether the outcomes delivered met the expectations of users or whether people are disappointed.



Often – as you will see from these stories – the reality falls somewhere in between.

Sometimes people found their way to good outcomes in spite of red tape or errors while overcoming gaps in service, misunderstandings and difficult processes. Sometimes the hurdles felt so confronting that people questioned whether the journey was worth the toll.

The reports reveal the scope of the reforms needed to deliver the promise of the scheme in some key areas. They highlight changes that NDIS participants want to see to the way the Scheme communicates with clients and manages the NDIS market and workforce.



Some themes included:

- A lack of clarity and guidance about the operation of the scheme
- Labour intensive reporting and documentation requirements taking months or years to resolve
- Mistakes and mishandling of documents, including lost plans
- A lack of knowledge and responsiveness from local area coordinators
- Extensive wait times for support requests and notifications
- Unsatisfactory and limiting recommendations for supports
- Excessive treatment and service costs, including price gouging
- A limited availability of services in the ACT and service delivery constraints
- A lack of non-NDIS community services
- Inadequate quality and training of support workers

But they also speak to the transformative and beneficial changes that the scheme has brought into the lives of people with disability in Canberra. Against all odds, dozens of reviews and two changes of government, the NDIS has transformed the lives of Canberrans with disabilities. Despite many kinks in the road, none of us wants to go back to the capped and rationed system before the NDIS.

On behalf of AFI, we would like to thank all the contributors to our stories, our designer Rob Donnelly; our photographer Andrew Sikorksi, our funders and partners, especially Women with Disabilities Australia and the AFI team.



Craig Wallace
Head of Policy



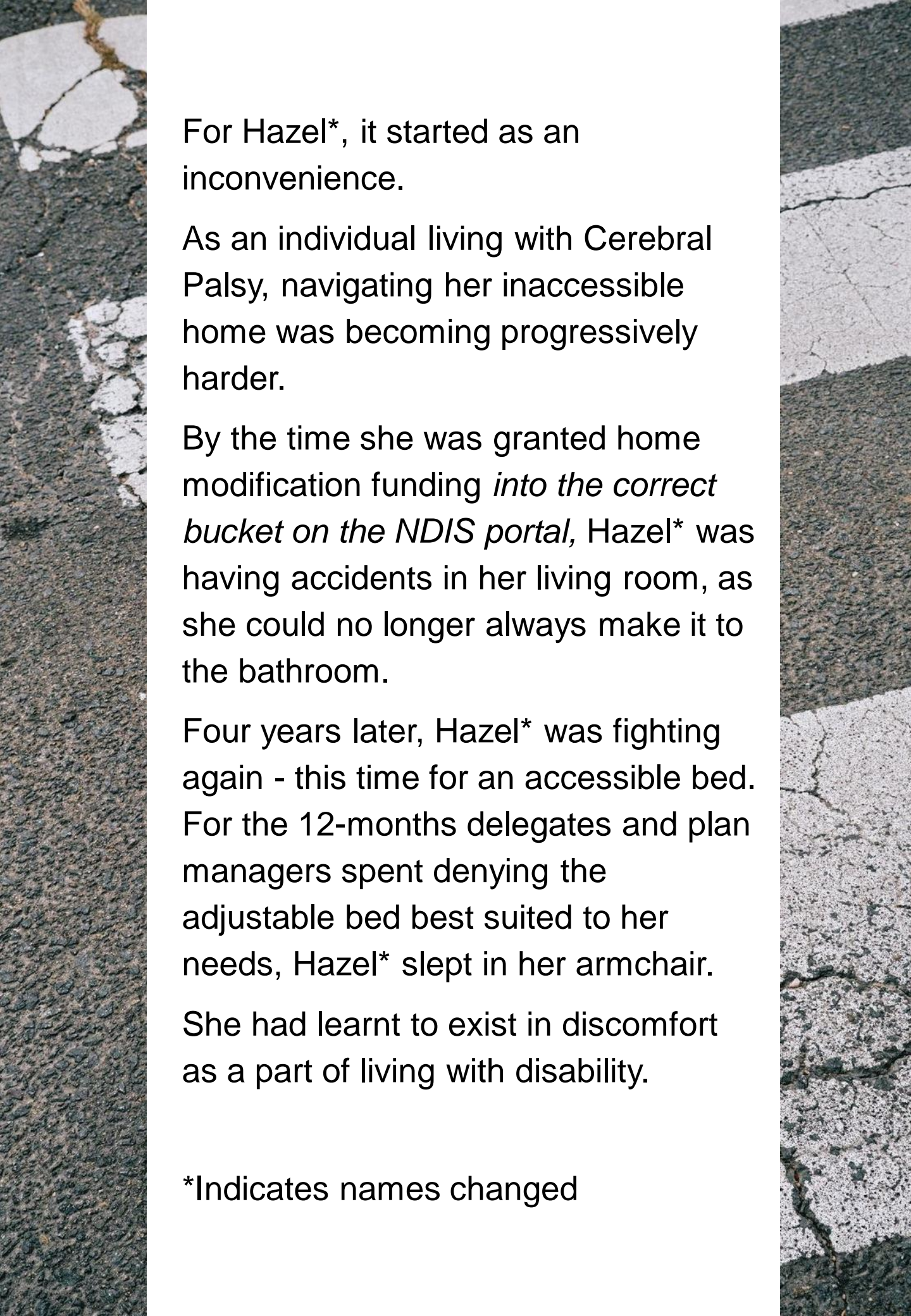
Roslyn Emmerick
Senior Policy Officer

SECTION 1

WHAT

PEOPLE

TOLD US



For Hazel*, it started as an inconvenience.

As an individual living with Cerebral Palsy, navigating her inaccessible home was becoming progressively harder.

By the time she was granted home modification funding *into the correct bucket on the NDIS portal*, Hazel* was having accidents in her living room, as she could no longer always make it to the bathroom.

Four years later, Hazel* was fighting again - this time for an accessible bed. For the 12-months delegates and plan managers spent denying the adjustable bed best suited to her needs, Hazel* slept in her armchair.

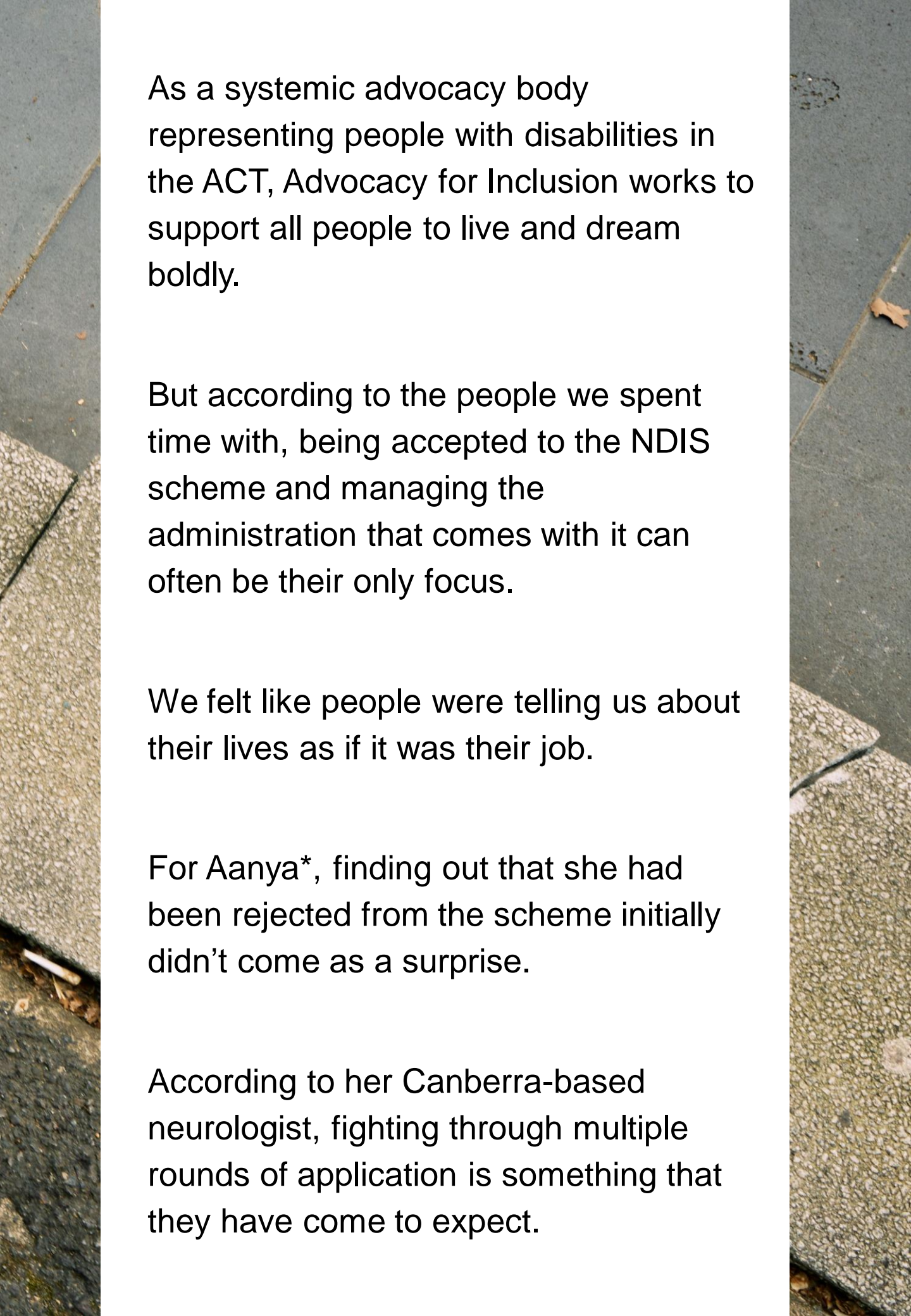
She had learnt to exist in discomfort as a part of living with disability.

*Indicates names changed

As one of the 550,000 users of the National Disability Insurance Scheme (NDIS) in Australia, Hazel's* story is not unique.

Over the course of the NDIS Review Consultation Sessions and Appreciative Inquiry Interviews, we heard many tales just like hers.

Stories of individuals asking for comfort, for safety, and to maintain their dignity, only to be denied.



As a systemic advocacy body representing people with disabilities in the ACT, Advocacy for Inclusion works to support all people to live and dream boldly.

But according to the people we spent time with, being accepted to the NDIS scheme and managing the administration that comes with it can often be their only focus.

We felt like people were telling us about their lives as if it was their job.

For Aanya*, finding out that she had been rejected from the scheme initially didn't come as a surprise.

According to her Canberra-based neurologist, fighting through multiple rounds of application is something that they have come to expect.


Aanya* took the directions of the online NDIS participant pack on face-value. She didn't know just how much evidence would be required to give her a fighting chance of being accepted.

Pages and pages of information. Thousands of dollars' worth of health care reports. And just the right phrasing to tick all the boxes.



Many individuals we advocate for agree that the NDIS application process is stressful and overwhelming.

With its own language and vocabulary, and with limited information available online, would-be-participants turn to Google and word-of-mouth recommendations to help them through the process.




As a person with a brain injury, Peter* remembers little about the initial application process. He managed to be accepted to the scheme through a process of trial and error.

What does stick out is that he wasn't well supported in his transition from the hospital back into his everyday life.

"I know that I started seeking out services while in hospital, and that there was a good catalogue of options to choose from, but I wasn't guided in the way that I could have been. It felt like the staff that I interacted with didn't have enough broad experience to refer me to the local services that I could access."

Unlike individuals in Victoria who receive a brain assistance starter pack, Peter* found that his doctors were unable to recommend specific services that would support him as a brain-injured person.



Disability Gateway – described as the one-stop-shop for “*information and services to help people with disability, their family, friends and carers, to find the support they need in Australia*” has failed to attract or meaningfully assist any of the individuals that we spoke to.

Users instead opt for desktop research to identify functional and domestic supports that are suited to their needs, as they’re often unable to locate useful, relevant information on the NDIS website or through the Disability Gateway portal.

For many, the questions continue to outweigh the answers:

What types of rehabilitative exercises do I need to do to maintain my function?

What domestic services will help me to simplify my life?

What am I allowed to try?

For Clare* accessing support for mental health issues on top of her physical disability has added another layer of complexity.

“My current plan is approved under the psychosocial category, but I have a physical disability also. There are certain things that I can’t get approved for my disability, because they don’t align with my mental health goals.”

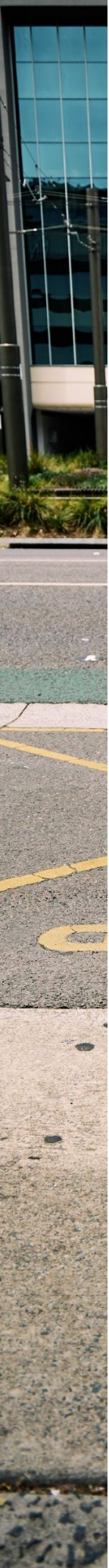
Like many of the individuals we advocate for, Clare* grew sick of waiting for her initial application to be accepted. Soon, she turned to completing an application under the psychosocial category, as she had more information readily available related to her mental health.



As it turns out, her initial application – lodged in person – had been lost by staff.

She was waiting for an approval that would never come.

Interactions with staff across the board were reported to be frustrating and unsettling.



As a person who is often not well enough to speak to planners over the phone, Nadia* chooses to rely on email communication.

Like many of the scheme participants we speak to, she is tired of sending emails to planners and local area coordinators, only for them to be forwarded up the chain.

As they wait patiently for replies that don't come soon enough or not at all. NDIS participants grow frustrated, and their needs go unmet.

Witnessing a high turnover of NDIS staff, they are forced to provide the same information time and time again to people who are unfamiliar to them and who don't have the time to understand their needs.

For Nadia*, the interactions she *has* had with planners and delegates have been tense and frenzied.

“A NDIS planner reviewing my application for home modifications once almost threatened me to say that if I didn’t talk to them then and there, that certain things weren’t going to work in my favour. They were going to reject my application.”



A common experience shared by the participants we spoke to was having their preferences disregarded by the staff members and providers they rely on for support.



Interviewees frequently shared the limiting recommendations that they had been provided, which demonstrate an unfamiliarity with their unique and specific needs. When asked how they had been let down or disappointed, answers came thick and fast:

One had been recommended an 'accessible' bed that would isolate them from their partner of 43 years – preventing them from sleeping together like any other couple.

Another was provided with a wheelchair model that didn't fit in their car – meaning that they had to purchase an identical model to store at their workplace.

One participant had even been asked to relocate, instead of being supported to modify a home that they loved.

When asked about interactions with support workers and medical practitioners, our interviewees disclosed a slew of further issues, specifically around the inadequate training of support workers and the unavailability of essential services.

Hazel* has found that she is almost never satisfied with the quality of cleaning and assistance she receives from disability support workers.

“I remember once hiring a young support worker who had obviously never cleaned a house in their life. I had asked them to give the floors a good mop – only to watch them traipse around the house with the mop in the air, only occasionally dabbing the floor.”

In Hazel’s* eyes, hiring an unqualified support worker is a disheartening waste of energy and funding. Spot cleaning is something that she can do herself. What she *needs* is support with the things that she cannot do alone.



Others we spoke to recounted more sinister issues, like witnessing support workers drop food on the floor only to pick it up and put it back in the fridge for consumption.

Many have reminded support providers to properly wash their hands, to not leave sharp items in the sink and to wear masks in their presence. One interviewee waited 90 minutes for a support worker to arrive at their first appointment.

According to the NDIS participants we advocate for, witnessing health and safety violations and having workers arrive late or not at all is commonplace.

When accessing medical providers and specialist services, interviewees recalled waiting up to a year and a half for appointments or travelling interstate for services unavailable in the ACT.

Almost all of the individuals we spoke to referenced long wait times for appointments and services, and frustratingly, being overcharged as a NDIS participant.

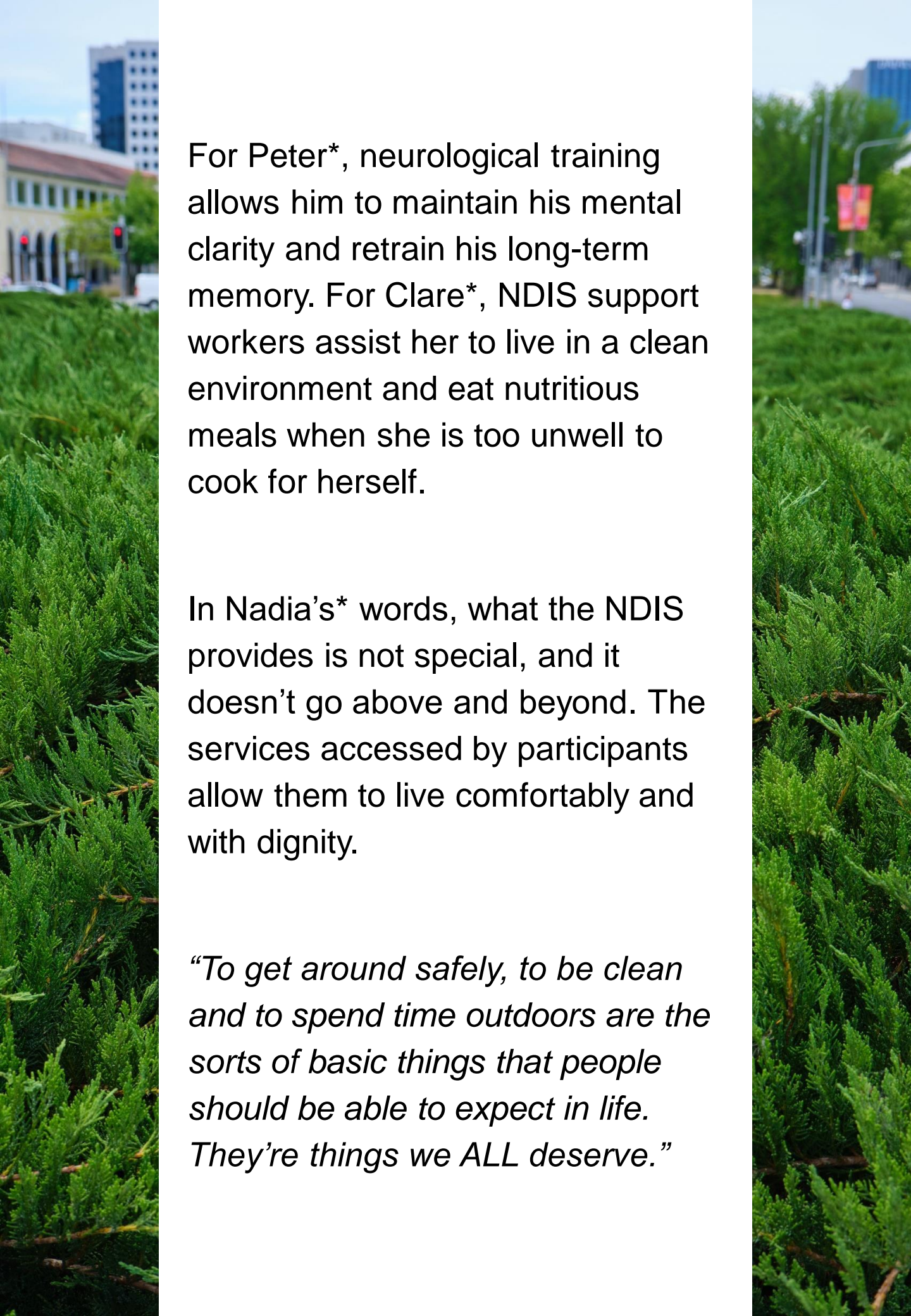
In 2021, nearly \$45 million NDIS payments were cancelled on suspicion of fraud, but the Australian Criminal Intelligence Commission fears that the misuse of NDIS funding may represent a much higher figure.

While medical practitioners and supports service providers see dollar signs above the heads of NDIS participants, individuals with disability are being swindled out of the funding that supports them to live.

Despite the many issues observed around the NDIS and associated services, the NDIS Review Consultation Sessions and Appreciative Inquiry Interviews revealed a crucial insight above all else.

When it works properly – the NDIS changes lives.

From allowing NDIS participants to shower and use the bathroom independently to providing opportunities for them to welcome disabled friends and family members into their home – the freedom provided by accessible modification cannot be understated.



For Peter*, neurological training allows him to maintain his mental clarity and retrain his long-term memory. For Clare*, NDIS support workers assist her to live in a clean environment and eat nutritious meals when she is too unwell to cook for herself.

In Nadia's* words, what the NDIS provides is not special, and it doesn't go above and beyond. The services accessed by participants allow them to live comfortably and with dignity.

“To get around safely, to be clean and to spend time outdoors are the sorts of basic things that people should be able to expect in life. They're things we ALL deserve.”

A blurred photograph of a city street at night. The image shows motion-blurred cars with their headlights on, and buildings with glowing windows in the background. The overall color palette is dominated by blues and yellows from the lights.

SECTION 2

THE

STORIES

Across 2023 we talked to a number of individuals who were participating in the NDIS in the ACT. We spoke to a mix of individuals – split by gender, disability type, service type and including people with and without regular contact and exposure to disability advocacy organisations.

Stories were solicited by open invitation and from organisations. Participants were remunerated for their time.

People were invited to be interviewed over several hours and have their stories recorded and curated.

These are stories from real people but all names have been changed and other details omitted to respect people's privacy.

We invited people to tell us their story, discuss the services they received before the NDIS, what it was like to join the scheme, the difference the scheme had made, issues with markets and support workers and how things unfolded along the way. We also invited them to highlight one thing that they might change in the transition if they met the CEO of the NDIS.

These are their stories ...

AANYA'S STORY

—

THE HARDEST THINGS

For some people the hardest things are the waiting and the struggle to be heard and to understand a complex scheme. But with help the journey can be completed and the wait is worth it ...



“In the beginning I found it really hard, at least in the first year, to figure out what I needed help with and where to get it and how to go about it.”

Aanya

As a person with a genetic disability, my condition and its influence progresses over time. I had never looked into the NDIS when it was first piloting and launching – partly because I didn't know what I needed, and partly because I thought that there was some kind of income test that I would have to do to join.

It was only when my husband and I were moving into a new house that I decided I needed handrails and other modifications to make the house a little bit more accessible.

When I rang around to community groups for support, the first question I got from many was, “*are you on the NDIS?*” A lot of places only said yes to NDIS participants, so I found that they weren't able to help me.

I first got started on the NDIS in March 2020, during the height of the COVID-19 pandemic while everything was shut down. It was a strange experience.

The NDIS basically has its own language and vocabulary, with all different terms and nuances that you won't know unless you were familiar with it, so I found it confusing.

I wasn't surprised that my first form was rejected. I had heard it said over and over – *“everyone gets rejected the first time anyway”*.

Once I'd figured out the form it had seemed easy enough. It wasn't like it was 100-pages. But my neurologist had never done a NDIS form before, *and we took it all on face value.*

The second application was all about figuring out what information was actually needed.

I took on the help of many to get me there. I needed notes from several different specialists, and I also approached an advocacy service. They told me that I needed a functional occupational therapy assessment, which I didn't have at that time.

In fact, the disability advocate I met was the first person to actually explain things to me.



Now that I have access to NDIS funding, I can finally get some help with cleaning, meal preparation, and tasks around the house. I've had accessible renovations funded too, allowing me to have small ramps and railings put in.

I tend to fall, and before, my own bathroom didn't feel safe. My old shower was hard to negotiate. My old toilet was very low, and my wheelchair doesn't lower.

For years and years, I'd just made-up ad hoc solutions for even the most basic things.

I wasn't able to stand up from the toilet on my own. The modifications I have received have taken away something that was an unpleasant part of my day, every day.



The hardest thing I've found has been the waiting. It took a year to get everything together for my home modification. There was a long gap between submitting my requests and finding out that they had been approved.

Even then, there are not many builders who are doing accessible modifications and so the waiting lists are long. When it was finally my turn to get started, the business that I was working with had collapsed. *I had to start all over again.*

It's definitely been difficult to access health services and find support workers too, and when you do, they're also overrun with requests. I don't have a Canberra-based local area coordinator at the moment, so the advice that I can get from them is limited.

Lots of the information and recommendations that I have received have come from informal sources, rather than from the NDIS website.

I rely on sites like Mable and Hireup to find support workers, and sometimes recommendations from Facebook. There's a Facebook group that I use which connects people with my condition.

I wouldn't even know where to start if I had to use a registered provider.

I'm also quite limited in the times that I have available. I don't have much energy after work, and usually I just crash, so I have to fit in most of my support hours over the weekend when the prices are a lot higher.



**That's the thing – I feel like
the scheme assumes that
people like me never work.**

In reality, I live to work.

**My background is in
population health.**

Prior to the NDIS, I found that I was getting so fatigued at work that I would become physically stuck at my desk for hours at a time. I couldn't even go to a meeting room or the bathroom because the effort of doing those little movements was taking all of my energy.

Now I have a wheelchair, but I don't have an accessible car that I can take it in. *There are all sorts of problems that compound.*

My solution was finding an identical wheelchair that I leave at work for the days when I can't work from home. My funding for support workers is quite small, so there is no way that I could pay for someone to come with me in the morning to set it up for me.



My brother has the same condition and level of function as I do and yet his NDIS funding package is more than double mine.

“It feels like it’s just luck of the draw.”

I probably didn't get a great plan initially because it all hinged on what I managed to think about and remember in the short initial meeting with my local area coordinator.

Sometimes I just wish I could be supported by a person who actually has the capacity to spend time with me and who knows me.

The language that the NDIS uses is also far too formal and full of legal terms. I really worry about all the people who could be falling through the cracks. People with intergenerational disadvantage perhaps, who maybe can't get support from their community like I can.

I'm a first-generation migrant and don't have much family in Australia with knowledge of how these processes work here, but even then, I have people around me and have a strong educational background.

There are definitely other people who aren't as lucky who still need help.

At the moment, my main informal support is my husband, and he fills in the gaps for the supports I can't access, but he's been suffering from carer's fatigue for the last 10 months.



One of the goals in my plan is to be able to get out and do some more fun things when I can. *We could both do with that.*

It's hard because I think my research brain gets used up at work, and there's always so much to think about.

If I want to go to the beach – *are there beach wheelchairs that I can rent?*

If I want to go to a gallery – *is there a ramp to help me access the building I want to go into?*

I've clearly really benefitted from the physiotherapy and occupational therapy I've been able to access recently, but I need to keep working on how I can be able to get out and explore.

Even then, one of the things that really frustrates me is when people take advantage of the NDIS label.

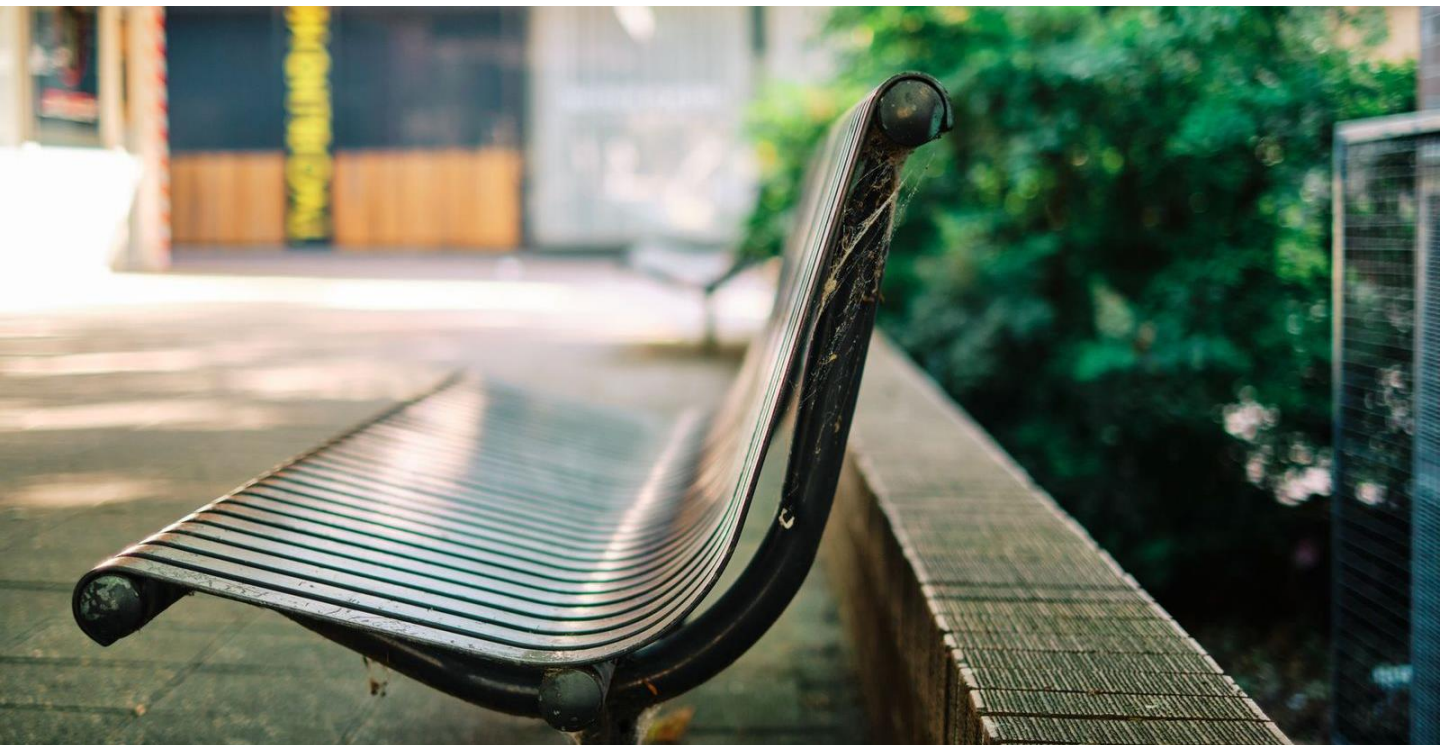
There was a physiotherapist I had wanted to stay with long-term who was charging me a lot more because I was a NDIS participant. That just doesn't make sense to me as my plan is completely self-managed.

I told them - "You're not having to do anything extra for me. Why am I having to pay \$40 more than the average person?"

A lot of people don't fully understand my disability either because it's quite rare. It might help if the NDIS had the resources, time and capacity to get to know people, and to learn about them. But right now, it seems like they just don't.

My goals at the moment are meaningful to me. I want to keep working because work is central to my identity. I want to be able to do fun things and live a good life. *But it's up to me to make sure that I get to.*

At the moment this is what I have, and I'm grateful for the support I can access – but I won't stop hoping for it to be better.



NADIA'S STORY

—

IT TOOK A LONG TIME

Getting entry to the NDIS can feel like a job application. It can involve a lot of work, many assessments and reports and take time to hear back. And for some that's just the start ...



“... Luckily, I didn’t have much trouble getting accepted, but it just took a really long time. I think 7 months went by before I heard that I’d been approved, despite the dossier of medical reports that I provided.”

Nadia

When I was applying to the scheme, I relied on my doctors and specialists for evidence that I had done everything I possibly could to get better.

I wanted to make it clear that there weren't any treatments on the horizon that were going to help me.

Personally, I've been sick with a neurological disease for over a decade and have been a NDIS participant for a number of years now.

I have Multiple Chemical Sensitivity, which causes me to be highly sensitive to all sorts of chemicals.

Fabric softener. Perfumes. Plastic and foam. Paint smells. Diesel fumes. All the things that make people sick in very large doses make me sick in even in small traces.

I experience ocular migraines regularly and can lose the ability to speak. I've lost sensation in half of my body in the past and find that I can't walk, or that my throat closes up. *It can be really scary.*

Between managing my symptoms, attending medical appointments and managing support workers, being ill really does feel like a full-time job.

I'm lucky to have access to an enormously generous NDIS funding package to support me getting out into the community, but unfortunately, I'm often not well enough to use it.

When I am feeling up to it, I enjoy attending art exhibitions and going to art classes. I find that cultural institutions do a great job at accommodating me.

A major struggle I have is in finding support workers and specialists who are willing to cater to my needs in the same way.

Unfortunately, I'm sensitive to conventional cleaning products, so I can't employ someone who has just cleaned someone else's house and used Spray N Wipe, for example.



The service agencies that I use keep sending people who may or may not be properly briefed, or who don't take the risk seriously. Some agencies just seem to throw up their hands and say *"yeah, that's a bit too hard"*.

It's difficult because when people decide that they can't cater to my needs, the pool of support workers that I can access shrinks even smaller.

There isn't a central resource for finding cooperative support workers for people with my condition. *It really is a matter of going down many different avenues until I find what I'm looking for.*

As a wheelchair user and someone who is often needing to rest, I employ support workers through the NDIS to help with cooking, cleaning and meal preparation.

Previously, I relied heavily on my husband and friends. It's been an enormous relief to have outside help.

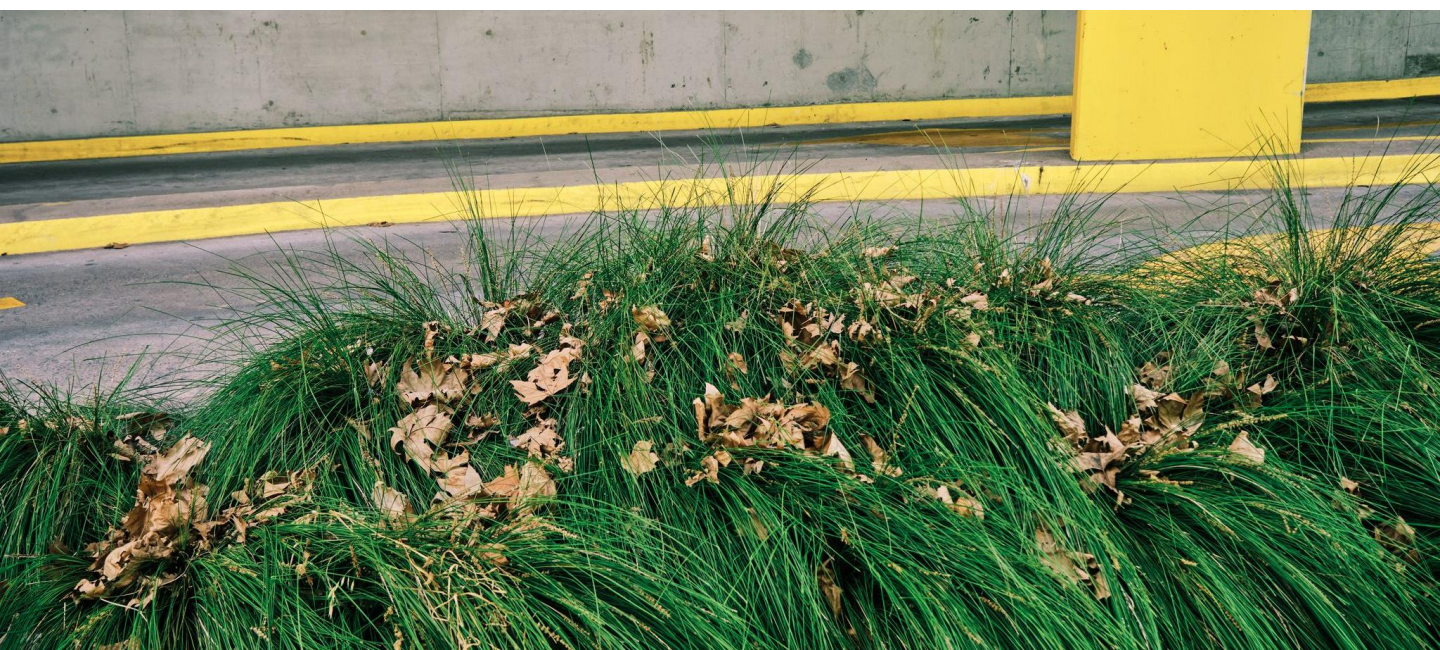
I used to use Mable to hire support workers until I had several safety incidents with them that weren't taken seriously.



Once, there was a lady who was chopping up some fruit for me and dropped several pieces on the floor. *She thought I wasn't watching and then just picked them back up again.*

When I later checked inside my fruit container, I could see visible specks of dirt on the fruit that she had dropped.

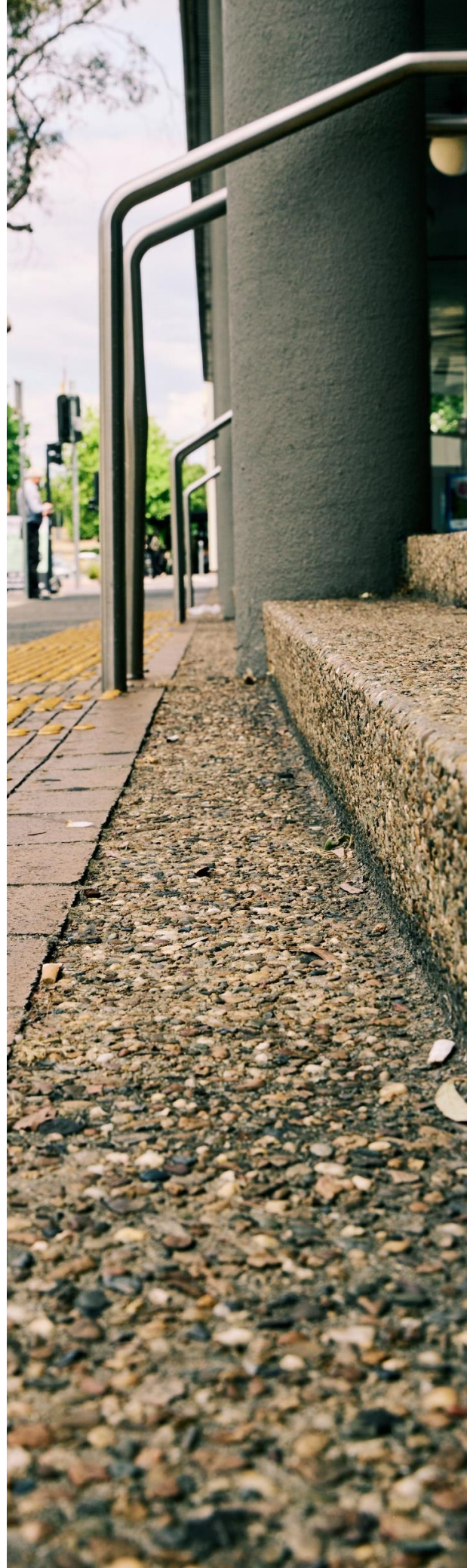
“I reported that to Mable because she told me she also cooked for a man who was completely vision impaired, and I thought he would want to know, or at least be told that a report that came in and he could make a judgment call. *But they wouldn't do anything about it.*”



Another support worker didn't listen to my instructions or read the sign on the front door and caused \$14,000 worth of property damage to my home that risked my health.

I had to move out while repairs were done and Mable again didn't take it seriously, even though the worker confessed straight away.

It took months and months of chasing their insurance company and I had to spend my own money to move out during repairs.



Often, it feels like people are eager to take financial advantage of you as a NDIS participant.

I once had a man coming over to clean, and when I asked him what the job would cost, he told me that he would send the invoice straight to my plan manager. He said that I didn't need to worry about the cost, as I wouldn't see the bill.

I felt really uncomfortable to think that he wanted to just make up however much he was going to charge me and send it off to someone else.

He also arrived unexpectedly with a second man who I hadn't met. *They both showed up at my house, which was intimidating for me as a woman on my own.*



I've experienced similar feelings of unease in my handling with the NDIS, where they have undermined my choice and control.

My preferred method of communication is always email, as I'm not always well enough to talk on the phone.

I've had NDIS staff ring me saying that I needed to talk to them right away and answer questions on the spot.

A NDIS planner reviewing my application for home modifications once almost threatened me to say that if I didn't talk to them then and there – if they didn't disregard my request for an accommodation by allowing me to reply by email – that certain things weren't going to work in my favour. They were going to reject my application.

When I am able to send emails, I often find that they get forwarded up the chain to the main NDIA email, rather than being addressed in a timely manner. It's frustrating that I can't communicate with the people assessing my applications for the things I need to live.

When the NDIA staff assessing applications change jobs and there is no record of what they've done, the responsibility falls on participants to provide the same information time and time again.

There are all sorts of everyday frustrations that become wearing over time.

I've also hired support workers who have had to be reminded to wash their hands or told not to wash the mop head in the kitchen sink after mopping the bathroom floor.



**It feels like these are things
that should be intuitive.**

***It shouldn't be our burden to
look after these things.***

Once, when I travelled by plane home from Sydney to Canberra, I remember waiting ages for my wheelchair to come through security, having just experienced what was already a taxing journey.

My wheelchair had been damaged by the airline on the departure leg, and my booked escort hadn't arrived to assist me.

I was rushed through the perfumed duty-free section of the departure lounge as a result, despite having asked to avoid it. *I became unwell immediately.*

The wheelchair queue hadn't been staffed properly either, so I was verbally berated by Border Security while I waited for help. It was a horrible experience.



On arrival in Canberra, I found out that my wheelchair had been left outside in the rain in the middle of winter. *It was zero degrees.*

After having to sit in a soggy, wet, freezing cold wheelchair, I decided that I would never fly again. It feels like people don't appreciate the toll that these kinds of incidents take.

Regardless of the struggles I've had with getting appropriate supports, I'm still very grateful for the major wins that have come out of my NDIS packages.

Prior to having my bathroom door widened and shower screen removed, it was really difficult for me to shower by myself. My husband is terrific, but it took so much time and effort, and put us both in danger.

Now that my wheelchair fits into the bathroom and I have a bench seat, *I am often able to shower almost completely on my own.*

I now have a shower every second day, instead of once a week as I had been doing previously. You always feel so much better after a shower.



I'd love to make my garden more accessible too, so that I can make my way outside on my own.

You have to get around your house safely and be clean, and everybody needs to spend some time outdoors.

I think those are the sorts of basic things that people should be able to expect in life. They're things we all deserve.

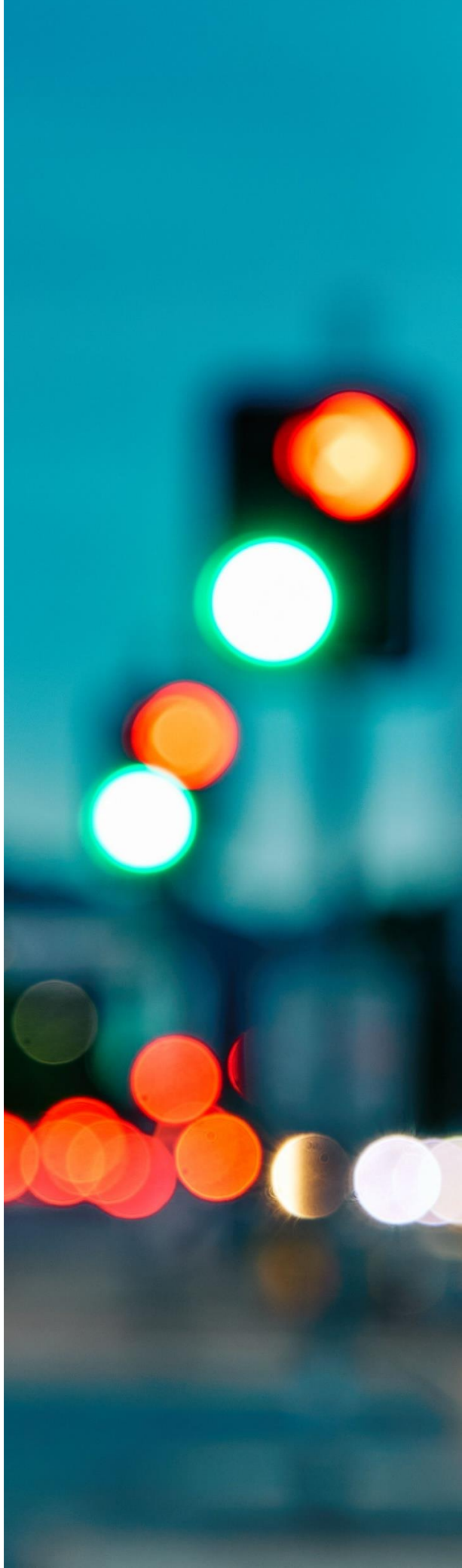


PETER'S STORY

—

SEARCHING FOR SERVICES

*Sometimes the funding is
there but the services
aren't available, or you
can't find the right
information on them ...*



“When I was in hospital, I remember being given a list of support providers, but not receiving any recommendations about who I should go to.”

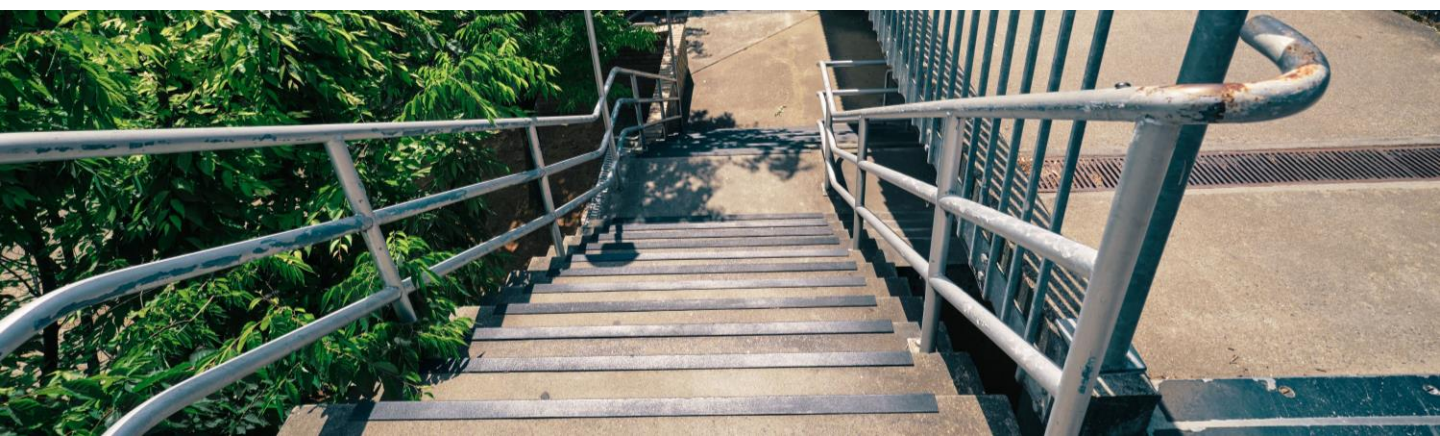
Peter

I have issues with my long-term and short-term memory, so there is a lot about the process of joining the NDIS that I can't fully remember. I know that I started seeking out services while in hospital, and that there was a good catalogue of options to choose from, but I wasn't guided in the way that I could have been.

It felt like the staff that I interacted with didn't have enough broad experience to know what would help me as a brain-injured person.

In my case, my brain injury was caused by a surgery which transported bacteria into my brain and caused encephalitis.

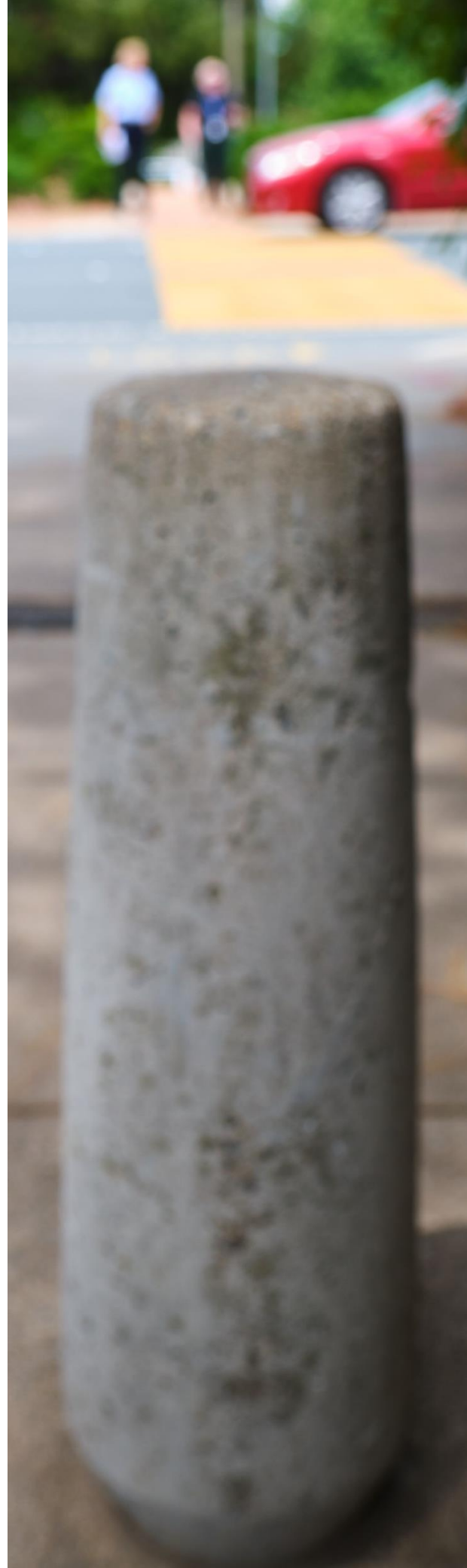
As a result, I can be sensitive to noise and getting out each day remains difficult.



Luckily, I didn't have to learn how to walk or talk again after my injury, but I have found that it causes me severe mental fatigue. *Building up my capacity is something that I have to continually work on.*

I ran into some issues around getting the right timing and evidence aligned to support my NDIS application, but it was fine once we got the ball rolling.

Thankfully, the process of completing the application didn't cause me tremendous anxiety – *I think because research is what I do.*



Prior to my injury, I worked in business strategy development in the space industry. My boss supported me really well after my injury, but I've found that I'm not suited to that kind of job anymore.

Recently I've transitioned back into policy development for a software company, but I still have to be mindful of taking on the kind of work that is better suited to me now as a person with a brain injury.

One of the major services I rely on to support my recovery is brain training. Twice a week I attend an exercise physiology studio that specialises in brain injury and has a program set up for me.

I find that their services help me tremendously. *After a session my brain just feels so much clearer. I feel calmer.*

At the same time, I believe that the clinic I go to is the only neurological training service in Canberra. That's a single point of failure right there.

There is definitely quite a bit of demand, so the clinic is frequently busy.

During a session, I have a full brain scan, which looks at all of the different areas of my brain and assesses how they're working. Typically, I'm wired up to a machine and have currents running through my brain. I'll then watch a movie for half an hour and the screen will react in line with how my brain is reacting.

It's all about teaching me new neural pathways.

I find that the service providers I go to have always been helpful, but it's often difficult to know where to find them.

Currently, I have a plan manager who helps me to navigate the supports that I can access, and I've previously worked with local area coordinators. I definitely feel that there is a need for extra help from NDIS employees to ensure that participants are guided in the right direction.

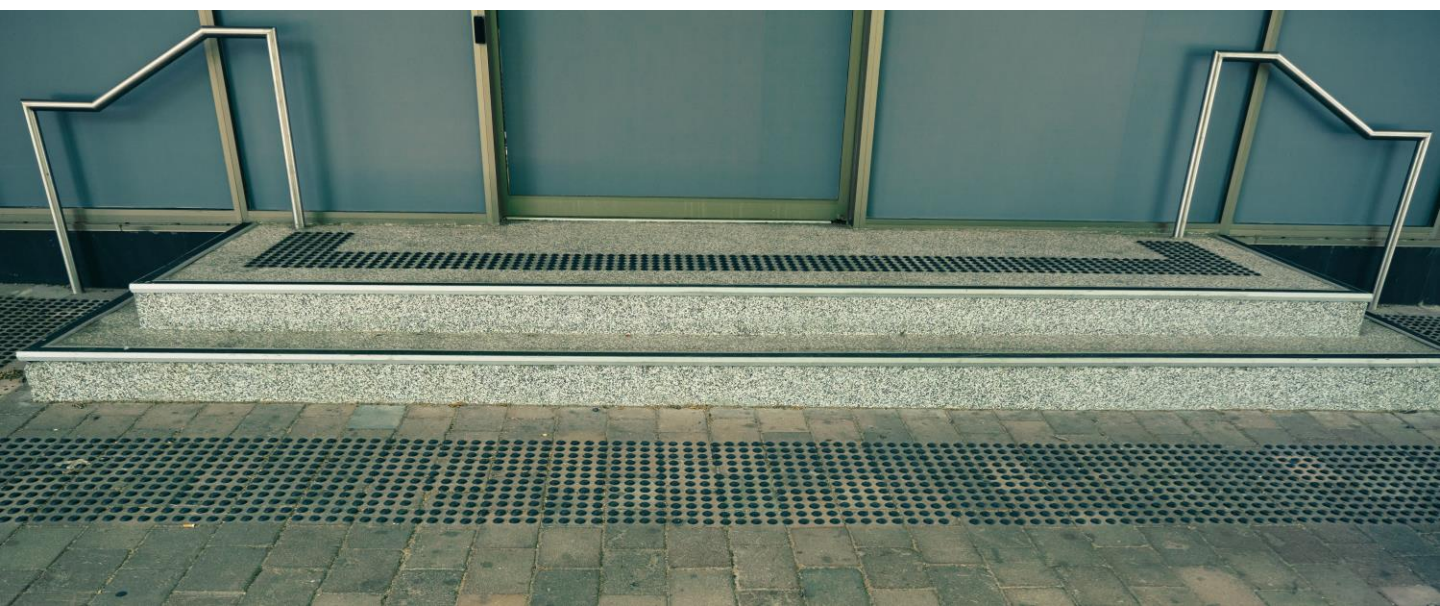
I'm not sure if the local area coordinators are necessarily the right person, but there needs to be someone who can help each of us out.

All of us on the NDIS should be able to go to a central person and say, *"I've got these problems, what do I need?"*

The scope of services that allow a person with a disability to live a meaningful life can also be so much broader than most people would imagine.

I was surprised to have been funded to get a coach to help me edit my first book. My writing was reawakened in hospital, and people were mainly encouraging me to just write about my injury. *Instead, I wanted to do something different.*

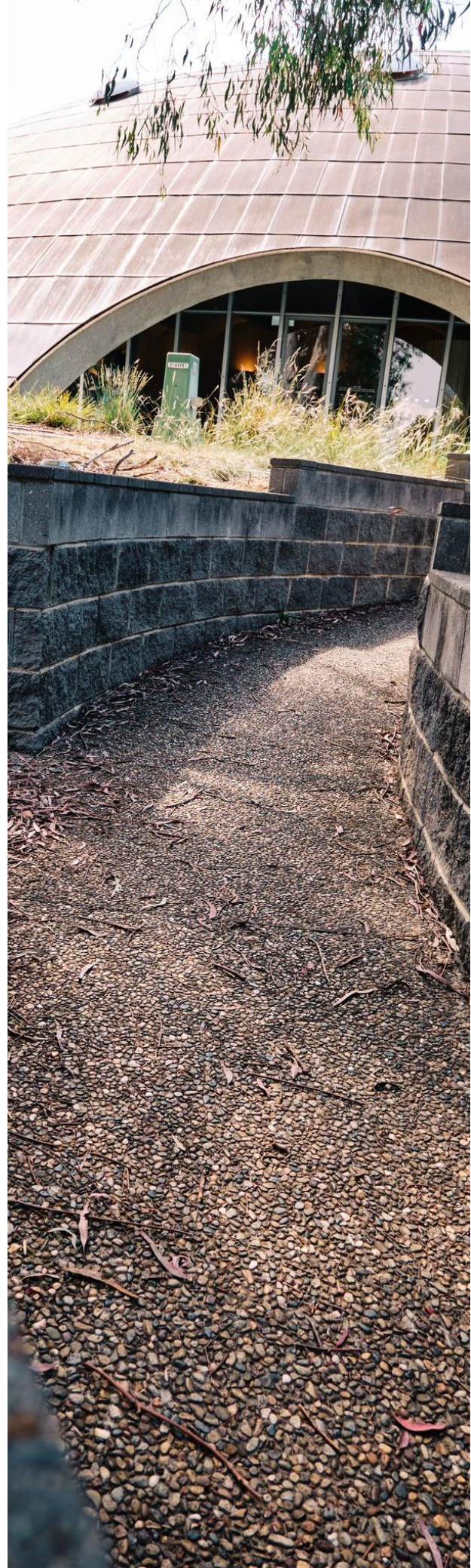
After losing my long-term memories, I set out on a mighty quest to find them. My experience emphasised just how important history is because it helps make us who we are.



I'm now writing a series of creative nonfiction history articles and books with a personal connection, where I dig into a historically significant location and tell my own story alongside it.

At the moment I'm seeking NDIS funding to secure a coach to help me with the book layout before I publish it.

It's difficult because my writing just wasn't a factor when I was first building my plan. It feels like you have to request a new plan each time you change directions.



Originally, the major goal of my plan was to increase my community participation, and this is something I'm still continuously working on. I joined the ACT Family History Society and am volunteering to do some strategy work on their behalf.

In order to get out and about, I often use support workers to help drive me from place to place. I did have an issue once with a driver that stuck in my mind. The driver took myself and my girlfriend to visit her new unit and then decided that they couldn't take her home.

I managed to get on the phone with them and apologised for not knowing that I couldn't bring her, but it made me wonder – *why did they let her come in the first place?*

I've since ceased services with that company and have found another provider that allows for companions to ride in the car.

I also find that the treatment prices are often hiked up when providers find out that you're a NDIS participant. My brain training sessions are fairly priced for the amount of benefit I get from them, but even then, they cost a couple of \$100 per week.

There is an opportunity to set people up to do those kinds of treatments at home, particularly if the demand at clinics is too great. *We could even link up with Sydney and Melbourne teams, and all help each other.*

I receive mental health counselling from an excellent practitioner, but I'm soon going to need to search for a new provider. I've been seeing the same psychologist for several years, but I really shouldn't have been able to.

Technically, my psychologist only provides a short time service. She's had to extend her time with me several times already.



The service providers I've seen have certainly been welcoming and understand disabilities, but the problem mainly lies in finding out where to go and what different kinds of programs are offered.

I know that hospitals in Victoria provide a brain assistance starter pack, but there was nothing like that given to me.

I took it upon myself to start up a brain injury support group to help other NDIS users find out what is available to them. Previously there was a similar program in my area, but it lapsed after the leader moved away.

Those kinds of services can be a lifeline for people while who are trying to navigate the system. And there's nothing like knowing you're not alone.

HAZEL'S STORY

—

I'M NOT ASKING FOR MUCH

A bed to sleep in and access to the toilet in your own home seem like simple requests but when tangled in red tape the simple can get complex. And that's where things go really wrong ...



“With every plan I think that I must just be asking for too much, but for me, I’m only asking for things that help maintain my dignity and allow me to participate in the ways that I want to.”

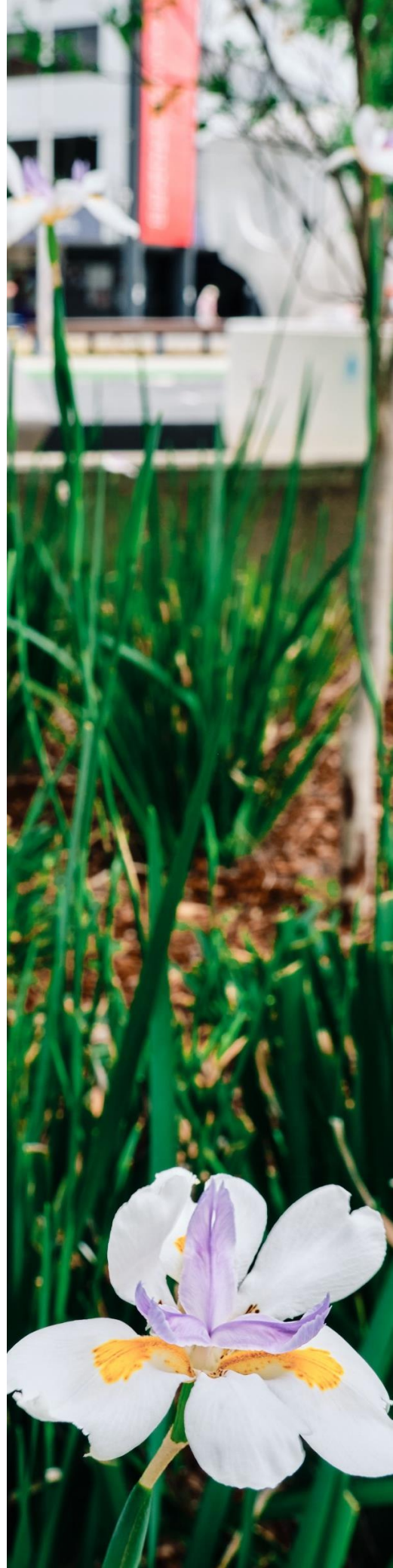
Hazel

As a long-term user of the NDIS, I've had some great experiences, but I'm also an example of how when things go wrong – *they go really wrong.*

I was diagnosed with Cerebral Palsy at the age of two, having been born at 26 weeks. There are a range of symptoms associated with the condition that I work to manage.

In my most recent plan, I applied for an adjustable bed to help me better work through my symptoms of swelling in my legs and acid reflux.

I can't lie down flat anymore, so for the last 12 months I've been sleeping in my armchair.



The NDIS came back with an option that wouldn't allow myself and my partner to sleep next to each other. They didn't seem to understand that we weren't requesting funding for his half of the bed, as we have always slept together.

By limiting me to the model they approved, I would be relegated to the other end of the house in our spare room, which is the only place where we could fit the bed that they chose. My partner wouldn't be able to hear me if I called out for help. I would also be at the opposite end of the house from our toilet and accessible bathroom.



I remember thinking, “so you’re saying that my husband and I – that my partner of nearly 43 years – can’t spend our night times together like any other couple? And you want me to be in the far end of the house where I’m not safe?”

I requested a review and a conversation with a delegate, who did actually agree to speak with me. After 5 minutes on the phone, they agreed that the situation was ridiculous. *It was solved just like that.*

A major issue I find is that addressing even a minor miscommunication turns into a really long-winded process.

It's as if your request falls into a void, until 6 months later you receive a verdict that may not be close to the outcome you were hoping for. By then, you might be halfway through your plan, or have to reserve funding until the next round of application.

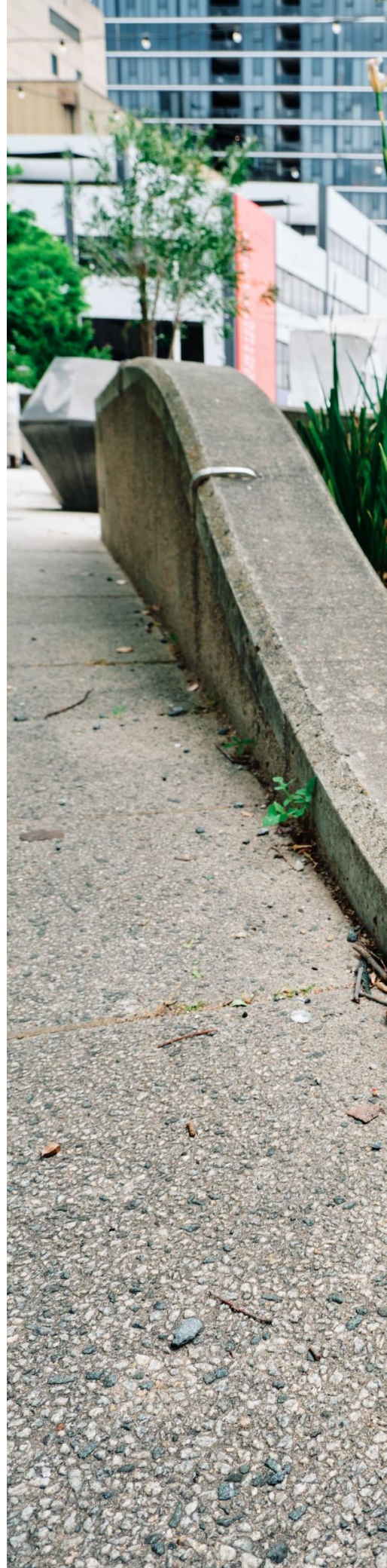


Another problem I've run into is the varied quality of support workers. On a weekly basis I receive domestic support, including weekly cleaning and general maintenance.

In 2014, I remember hiring a young support worker who had obviously never cleaned a house in their life.

I had asked them to give the floors a good mop – only to watch them traipse around the house with the mop in the air, only occasionally dabbing the floor.

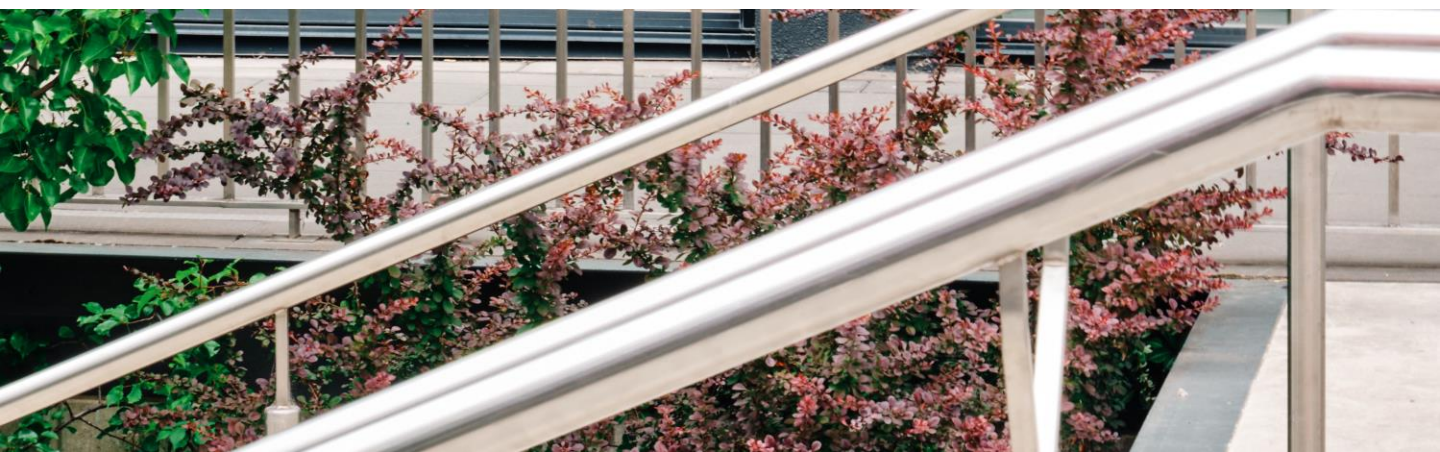
Spot cleaning is something that I can do myself. *I need people who are going to help me with the things I can't do.*



I'm not asking for much, but the house was almost never cleaned to a standard that I'm happy with when I was registered with a disability cleaning service, and I would often have to re-clean when the workers left.

More recently, I have enlisted the cleaning services of a sole trader who I am very happy with. I pay them above the NDIS rate because they do a great job. That is something that's really important to me, to ensure that the work remains competitive.

In addition to cleaning supports, my package allows me to have an exercise physiologist come to my home once a week and I go to a physiotherapist each fortnight.



I stopped accessing these services over the COVID-19 pandemic and I found that my muscular health deteriorated almost immediately. *“I’ve had a lot of muscle wastage in my legs, and I probably won’t get that muscle back.”*

In terms of my ability to get out into the community, I’m unfortunately still trying to limit my exposure to COVID-19.

I wish that the scheme would take PPE equipment into consideration when it comes to funding. I refuse to go out without a P2 mask on. *I’ve spent a lot of money out of pocket for my PPE since the beginning of 2020.*

Interestingly, I’ve found that options for community engagement have reduced since the introduction of the NDIS anyway.

Prior to 2013, people with disabilities in my area were relying on small group community services, and over time we had established really strong friendships with each other. *We enjoyed doing things together.*

After the NDIS was established, the community services we used tried to adapt to the new funding models and it was a bit of a disaster. They just axed all the disability programs.

The scheme prioritises independence above everything else, but I think that people who feel more comfortable being in group situations should still be able to choose those options if they want to.

I really feel that we, as participants, have lost choice and control.

Another situation that highlights this very concept is the battle I went through trying to get accessible home modifications.

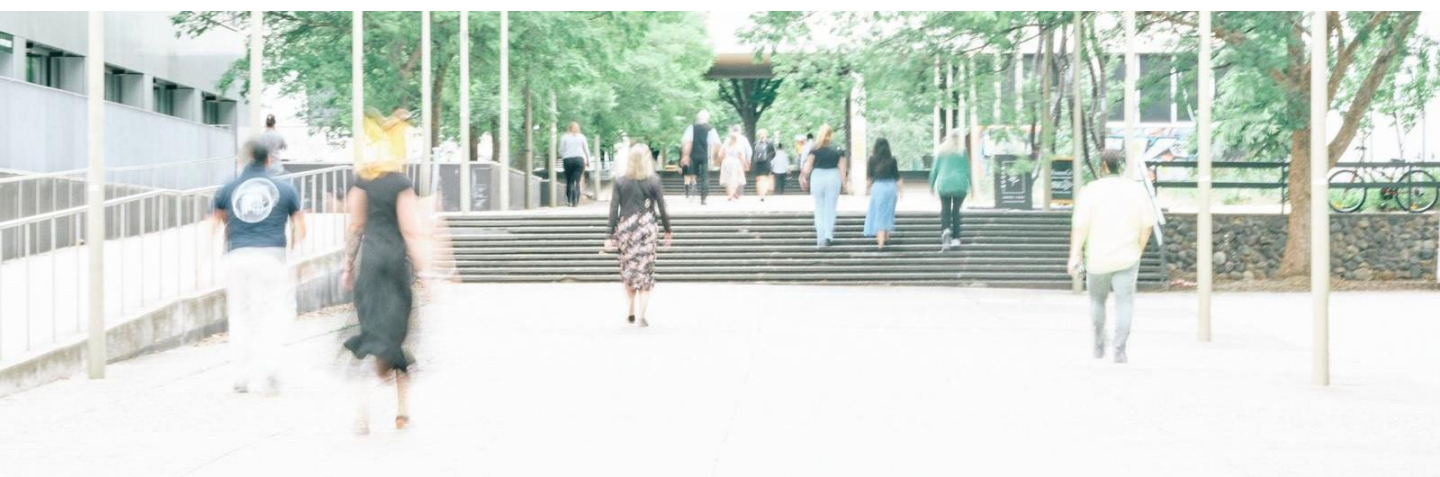
My husband and I bought our house many years ago when I was still very young and quite mobile. It was a split-level house, which we accepted at the time because we only planned to live here for 2 years originally. Thirty-five years later we're still here.



Of course, navigating the split-level flooring has become harder and harder as I've gotten older, and as surgeries and procedures have begun to increasingly impact my life.

Originally there were no objections from the NDIS over funding some accessibility modifications, and in fact, I was actually allocated a huge chunk of money in my plan. *The problem was that the funding had been assigned in the system to the wrong bucket.*

People I knew who were also in the system suggested that I just start putting invoices in, thinking that the money would be moved for me, but in the end, I was forced to wait for that plan to expire.



Next, we were told that my husband and I would be funded to move somewhere else that was already accessible. *They wanted us to move out of a home we loved.*

In reality, there wasn't, and still isn't, very much housing available in Canberra that is actually classified as accessible for a wheelchair user. Real estate agents have no idea what accessibility really means or looks like.

After a while I began to seriously struggle to navigate my house, particularly up to the bathroom. I had to put a walker on both the bottom and top level of the house. I was having issues with incontinence at the time, and occasionally had accidents.

It was distressing because it meant that if I had visitors at the house, there was always a risk that I would have to go through something embarrassing.

My options at that stage looked like going into a nursing home or supported living, without being able to live with my partner.

That's what the community saw as the alternative to me not being able to get an accessible home.

After four years of effort, I was finally approved to have my house modified in 2018.

My husband had done serious, long-term damage to his back at that point from helping me with transfers around the house. *It was a huge relief for us both.*

Prior to having a ramp out in on the front step, I would often have to meet my friends with disabilities in my driveway. One friend in particular used to reverse into my driveway and I'd get into the back seat of her car.

On the first day after my house renovations were finished, I was having a nap, only to come into my kitchen to find my friend making herself a cup of coffee. We laughed at the fact that she could essentially break into my house to make a coffee whenever she wanted, because she could finally get in by herself. *That was a really wonderful moment.*

I find that most of my problems have been solved through honest communication.

There's something to be said for being able to talk to a person face-to-face and explain your situation.

At the moment, the alternative is compiling 50-page reports that won't get read, and interacting with people who don't know you, or *have time* to work to understand you.

If I were to entertain an even bolder hope for the NDIS, it would be to ensure that people are allowed to try out all different kinds of treatments and activities and have the dignity to be able to fail sometimes like the rest of us.

That's difficult from a financial point of view. *But I think it's a very valuable way for people to learn how the world works.*

I really hope that this review allows us to get back toward the original vision for this service.

It's time that we're allowed to dream big.

CLARE'S STORY

—

FINDING COMMUNITY

Finding community is worth it when you are coming back from a difficult place. But first they have to find your lost NDIS form ...



“When I lodged my first NDIS application in person, I remember being told confidently that someone would be in contact. It took almost two years of radio silence before I found out that the office had lost it.”

Clare

The only reason I had physically travelled into the office was because I had heard from friends in the disability community that online applications often went wrong.

I had pulled together as much information as I could to fill out the forms, including testimony from my GP of almost 15 years.

The process was certainly quite draining and stressful. I kept thinking – do I have enough evidence? *Are they going to believe me?*

Across the time I was working on the submission, I took on the assistance of a mental health support advocate who had been assigned to me as a user of several psychiatric services.

I had been told prior to lodging that the wait time for approval could take over a year, but when I hadn't heard back in over 18 months, I reached out to the NDIS office.

**There was no record of
my application ever
having been lodged.**

***I'd been waiting and
waiting for an approval
that would never come.***

My appointed support worker made sure to advocate for me so that the approval process for my replacement application could be expedited, but by that time I decided to apply under the grounds of mental health instead.

I had recently been hospitalised and spent time in the psychiatric ward. I simply had more documentation outlining my recent mental health experiences that were readily available.

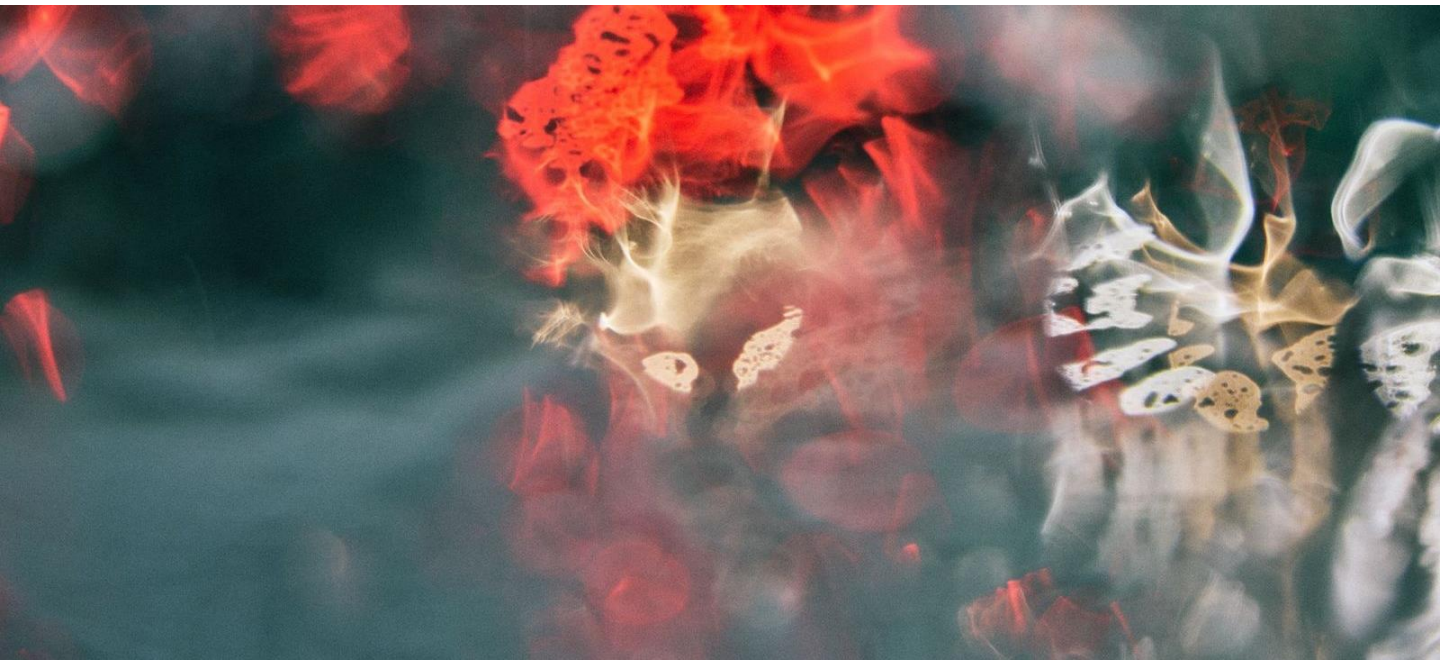
With my physical disability, it's really hard for me to get meaningful support from specialists because most practitioners have no idea what to do with me.



I have a very rare genetic disorder. I was only the third person in Australia and the 10th person worldwide to be diagnosed with the condition I have.

As a result, I found that before the NDIS was rolled out, I often didn't fit into the criteria to receive community supports. I wasn't completely immobile, but there were certainly things that I needed to access that I couldn't.

It felt like I had just fallen through the cracks.



Prior to being approved for the NDIS, I had a really traumatic experience that resulted in me making a suicide attempt.

Unfortunately, my two sons were removed from my care soon after.

I was in a really bad place and my house was in awful condition. Everything just felt too much.

One of the very first things I used my NDIS funding for was to hire a support worker to assist with getting my house into a cleaner state.

Thankfully, the decluttering process went well. By the time we were done, we had filled three skips of rubbish.

In regard to getting started on other programs, I remember that my support coordinator put a couple of things in place for me, but there were big gaps in time where I didn't hear anything from them.

Mostly, I was interested in hiring someone to help me with cooking, someone to help me with cleaning and someone to help me with gardening.

I didn't have a clear idea of what others supports I would be entitled to when I was first approved.

Three years on, I've now tried art therapy and float therapy. I also see an exercise psychologist and a psychologist regularly, which I find incredibly beneficial.

Unfortunately, there doesn't seem to be enough information available to help point you in the direction of what you can actually access. It's particularly difficult because each type of plan caters to a completely different range of assistance.

My current plan is approved under the psychosocial category, but I have a physical disability also. There are certain things that I can't get approved for my disability, because they don't align with my mental health goals.



**There's no consideration for
the fact that a single person
could be facing two
difficulties at the same time.**

It took at least two years after being approved to feel like I actually had a good plan in place that catered to all of my needs. Regardless, I know that since starting on the NDIS, my situation has definitely improved.

Without access to long-term care that the NDIS has provided, I think my mental health would be a lot worse.

I still find that a lot of the mental health programs I've joined are only offered to participants in the short-term.

You could be really benefiting from the support for 12 weeks and then you're left to fend for yourself.

I've had the same experience with at-home care after being discharged from hospital too. You go from being fully supported to being on your own.

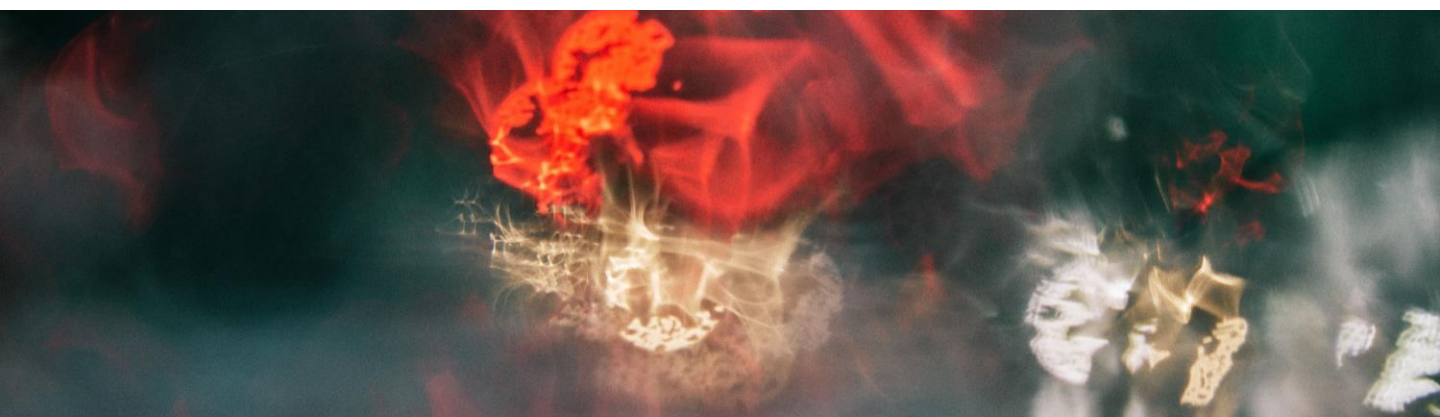
**One of the things that
has been really
beneficial in the
absence of long-term
support has been
having a community.**

Currently, I'm going through the legal process to have my two sons returned to my care, given that I'm now in a much better place as I have been previously.

I'm an artist and have recently started on my first ever commission, creating artwork for an exercise physiology clinic where I'm a client.

I'm also a board member for a community organisation in my local area. We hold one or two events per month that are low or no cost.

The idea is that women and non-binary people can come along and make new friendships, which is especially important considering how transient Canberra can be.



I'm currently contributing my voice in our regular planning sessions by advising on the accessibility of our program.

We once had an event at a venue that claimed to be accessible, but really wasn't at all. They had an accessible toilet, but it was located at the bottom of a very slippery hallway and a set of uneven steps, with no safety rail.

I was using my walker and could barely fit down the walkway. *If I had been in more pain than I was that night, I wouldn't have been able to go to the bathroom.*

On that particular night, I also wasn't able to engage with other people as well as I should have been able to. My walker couldn't fit in between the tables and chairs properly, so I was forced to stay at the very end of the table all night.

There were easily 50 or 60 people who attended that night that I weren't able to engage with – *people that I potentially could have been friends with.*

“The whole situation made me feel like people like me aren't important enough to worry about.”

When it comes to accessibility, people often think that if they check off the right boxes, they have done everything they need to do.

They don't take into account how things will work in real terms.



My role on the board is to make sure that something like that doesn't happen again. I've created an accessibility checklist to assess the venues that we use, and I try to think about all different sorts of disabilities.

It means a lot to me, because for a very long time, I didn't feel comfortable using my voice to advocate for not only what I needed, *but also what I wanted in life.*

Having the opportunity to speak on behalf of others who may not feel comfortable using their voices in those spaces feels so empowering.

And of course, I like being able to make people aware of things that people without disabilities take for granted – every single day.

