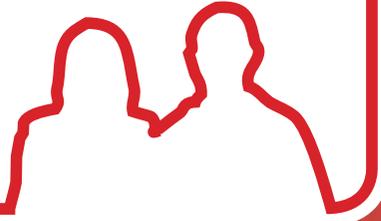


Every Australian  
Counts



**“Left out and locked down”**

**The experiences of people with disability  
and their families during COVID19**

Every Australian Counts survey report August 2020

# Our survey

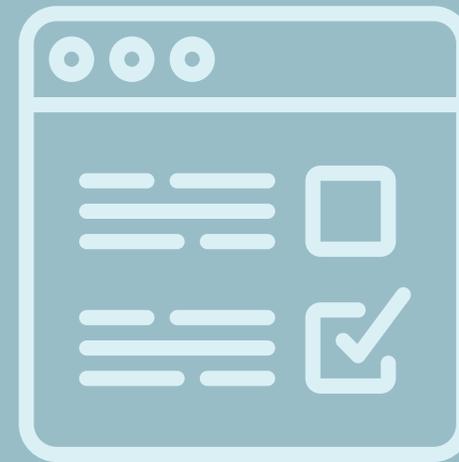
In May and June this year Every Australian Counts surveyed people with disability and their families and asked them about their experiences during the first wave of the Coronavirus pandemic.



**721** people responded. Most were people with disability and/or families.

There were a small number of responses from people who supported people with disability – such as advocates or support coordinators.

We asked them what impact the pandemic had on their lives, how they coped – and what they thought of the changes made to the National Disability Insurance Scheme (NDIS) during this time.



# Here's what they said

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People said they felt forgotten and ignored by government and by the community during the pandemic – despite the very real challenges that they faced.

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**32%** said their **costs** had gone through the roof, and many were struggling to make ends meet. Almost **50%** of people with disability were already in already **living in poverty** before the pandemic began.

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**Many people were stressed, anxious and stretched almost to breaking point.**

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And while changes made to the NDIS during this time helped some, others found themselves unable to get what they needed.

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Confusing, inconsistent and changing information contributed to people feeling even more overwhelmed and unsure of where to turn or what to do.

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For some the **complicated** NDIS processes and **lengthy** delays were **exhausting** and frustrating – but not life threatening. But for others continued delays threatened their very **health and wellbeing**.

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Despite all of this, there was, and remains, **very strong support** for the NDIS amongst people with disability and their families. They fought for it, they believe in it. They desperately want it to work.

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And they want to be partners in making that happen – they want the NDIA to talk less and listen more. They want to check changes before they are made to make sure they will work for them. And they want a simpler streamlined scheme so they can get on with their lives.

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# Here's what they said

Life for most people with disability and their families is constant juggle at the best of times. There are daily challenges, big and small, that can make life extraordinarily difficult. Add a global pandemic and life in lockdown and many of these already precariously balanced lives were thrown into complete turmoil.

People with disability and their families understand this pandemic is unprecedented. No one expects government and agencies to get everything right all of the time.

But the responses to the survey also make clear – when some people asked for help it did not come, or it did not come quickly enough.

In fact, the kind of issues raised in the often very detailed responses were the same issues we routinely hear about

when we ask people with disability and their families about their experiences with the NDIS. Confusing and complex processes, inconsistent and unclear information, lengthy delays, lack of flexibility and lack of help to navigate the maze are the issues we hear most about.

But throw in a global pandemic and lockdown life and these “everyday” NDIS issues have far more serious consequences. As the responses reveal they not only added to people’s stress and anxiety they also often stood in the way of getting what they needed to keep themselves safe and well.

This survey was conducted during the first wave of the pandemic. But as the events of the last two months have shown this is very far from over. So what people said would make a difference to them is now more relevant than ever.



**This is an amazing program. A credit to the country. It deserves to succeed in its objectives. But it does need more down to earth approaches. It needs less tiers of management. It needs common sense. It needs more disabled participants in the management process. It needs plain English.**

# The most common issues – at a glance

We asked people what problems they were having at the moment.

Here were the most common answers

**32%**

said their **costs** had gone through the roof

**22%**

said they had a child with disability who was now home and needed **more support**

**20%**

said they **couldn't find anyone** to provide services

**20%**

couldn't get support **online**

**20%**

couldn't **access PPE** (even before it became mandatory in Victoria)

**18%**

were **still waiting** for an NDIS review

**18%**

couldn't **move their NDIS funding** around in the way they needed

**17%**

said their services had **stopped altogether**



# “We’ve been forgotten”

**COVID19 poses a threat to everyone in the Australian community. Life in lockdown was (and remains) tough for many individuals and families.**

But the virus poses a particular threat to many people with disability. For some their disability or underlying health condition leaves them more vulnerable to illness - even death. Others are completely reliant on disability and personal care every single day. As a result they can't self-isolate or socially distance. For some, it is both of those things combined.

But for everyone there is also a real concern that the systems which should protect them or assist them will be the very thing that will let them down. That's not overstatement – that's concern born of bitter experience.

After people living in aged care, people with disability and/or chronic health conditions are arguably the next most vulnerable group in the community. And as a whole, they are also a group of people for whom the rules and regulations around lockdown have (and continue to have) a devastating impact on their daily lives.

And at the very time when they faced such extraordinary threat to their lives instead of feeling supported, many people said they felt forgotten and ignored.

## **There were the small things**

like no Auslan interpreters in early press conferences. Or captions. Or no mentions of the struggles of people with disability from Prime Ministers or Premiers.

## **But there were also the big things**

like their exclusion from additional income support. Unlike people on JobSeeker, people who received the Disability Support Pension or Carers Payment did not receive the additional Coronavirus supplement.

# “We’ve been forgotten”

People’s anger and frustration was reflected both in their responses to the survey but also in comments on our social media channels at the time.



Not once in any presser did Mr Morrison mention disabled or our carers! I feel left on a top shelf collecting dust, forgotten!



I know this has nothing to do with the NDIS but the inequity of the DSP and the Carers Centrelink funds not being doubled when all other Centrelink payments were doubled just cuts me to the core!! And no one seems to be talking about it. Why is that? It has my blood boiling!!!



I’ve given up fighting for the COVID payment. It’s never going to happen. I’m a second-class citizen and I’ll accept my fate as being less than to the rest of society now.



The government’s response to people with disabilities compounds my trauma. To be forgotten again and thrown to the scrap heap is traumatising and damaging.



Seriously why are we still being abandoned? We are the only group to have not been recognised explicitly in any of the support packages.

# “We need more help”

This sense of being forgotten or ignored was compounded by the additional stress people experienced during the early days of the pandemic and lockdown.

## Financial help

One important source of stress was the additional hit to already stretched budgets. Almost 50 per cent of people with disability live below the poverty line. **The additional costs associated with the pandemic and lockdown pushed many right to the edge.**

## PPE costs money

For some the extra costs were things like having to buy their own gear to keep themselves safe – critical items

like as masks and hand sanitiser. Even aids and equipment that people routinely bought before the pandemic began jumped in price once the lockdown began.

## So does online shopping

For others even paying \$15 to have shopping delivered to home was a cost they could not afford. Trying to shop online also prevented people from doing the things they usually did to make their budget stretch further – like buying home brands or relying on specials. Panic buying at the beginning of the pandemic also robbed people of the chance to buy cheap or preferred brands – the shelves were cleared of all but the most expensive items.



Help us survive this! Please! We are usually great budgeters with Plan funds but no one could have foreseen this pandemic situation and we have to keep my son safe.



This increase in expenses for grocery delivery fees, increase in purchasing home delivery meals and loss of income is now putting us into considerable debt that I cannot afford to repay. Soon it will become a choice of food or housing. We are both terrified for our future.

# “We need more help”

## Support through the pandemic

But it wasn't just extra costs that pushed many to the edge. It was also managing the impact of their disability (or their family member's disability) with limited or no support.

Some people who responded to the survey decided to reduce face-to-face support to try limit possible exposure to the virus. For others services stopped when lockdown began.

**Either way there were many people who were left at home to battle on with little or no help.**

Many of the respondents spoke of overwhelming stress, anxiety and exhaustion trying to look after themselves or their family member without the extra support they usually relied on.

For some online support was helpful – but for others it just did not work at all.

Some families were left to try and juggle home-schooling their child with disability with limited or no additional support from schools.

For families with an adult with a disability living at home, there were a different set of challenges. For some people with an intellectual disability or a cognitive impairment, the sudden change to routine was bewildering and upsetting. Their families were concerned with the impact of the lockdown on their physical and mental health. Others were worried about their own health as well.

Families whose son or daughter no longer lived at home were worried about what was happening behind closed doors in group homes – and whether their family member had everything they needed to stay safe and well.

Regardless of the particular circumstances what emerged was a picture of people and families trying to do their very best – **but many stretched to breaking point.**



Lockdown with no supports is literally destroying our children's resilience and breaking families.



Our heads are full of what's going on and just helping the person we are caring for without having bulk lots of info to read. Keep it very simple as we get emotionally drained.

# “We need things to be easier”

That sense of being overwhelmed framed responses to the questions we asked in our survey about what people wanted from the NDIS at this difficult time.

The overwhelming message was – **we have so much on our plate. We know much of what is making our life hard is not your responsibility. But your responsibility is the NDIS – what you can make that as simple and easy as possible for us so we can get on with the rest.**

And unfortunately for some people what they got from the NDIS was the opposite.

People with disability and their families are incredibly grateful for the life changing support from the NDIS. They fought for it and they are proud that the Australian government and the Australian people got on board and supported it too.

And while they appreciated many of the changes made by the NDIA during this time they remained frustrated by the slow pace of change and the confusing and inconsistent way many were implemented.



Didn't hear anything for six weeks. When we followed up again we were told the application didn't meet the criteria and it was rejected four weeks ago - but we didn't receive any notification. When we asked what the criteria were, we were told we would have to lodge a FOI request to find out what the criteria was.



I have to say that without doubt everyone I have spoken to in NDIS has been very supportive in trying to assist us but the rigidity of the rules has been very disappointing during this period.

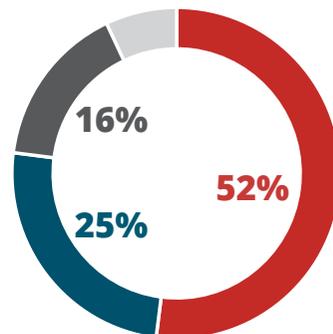
# Report card on some of the changes made by the NDIA during this time

## 1. Phone planning

In order to reduce face-to-face contact during lockdown, the NDIA held planning meetings over the phone.

- More than **52%** said they **found the experience positive** with a small number indicating that they preferred it to meeting face-to-face.
- More than **25%** said the **format did not work for them**
- **16%** had **mixed views**.
- A small number mentioned they had been successful in requesting a videoconference. Ironically a similar number had requested a videoconference only to be told no. Again – the NDIS was consistently inconsistent.

“Please understand that while checks & balances are necessary, people with disabling conditions are often just too exhausted & debilitated to be able to jump through too many administrative hoops. And many people, myself included, are completely on our own with no “informal supports” of any kind to help in the process.



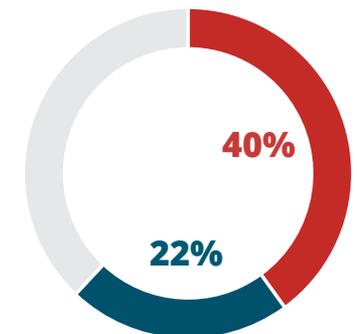
## 2. LACs and NDIA staff

Many commented that they knew more about changes made to the NDIS during this period than the person on the other end of the phone.

- **40%** of people reported that their LAC or NDIS staff member had been **helpful during this period**.
- **22%** reported that they had either had **no contact at all** – or when they did it was **far from helpful**.

“Our LAC is fantastic. Informative, doesn't give out wrong information, is willing to tell us they don't have all the answers and clearly goes and finds the correct answer even if it's not the one I want to hear.

“Please stop making this so hard. We are bruised and fragile already, COVID has made us even more vulnerable, and then we have to fight against the very service that is meant to be helping us. Please stop making our needs a battleground, stop assuming we are somehow trying to swindle services we don't need, and just let us have the NDIS that we were meant to get.



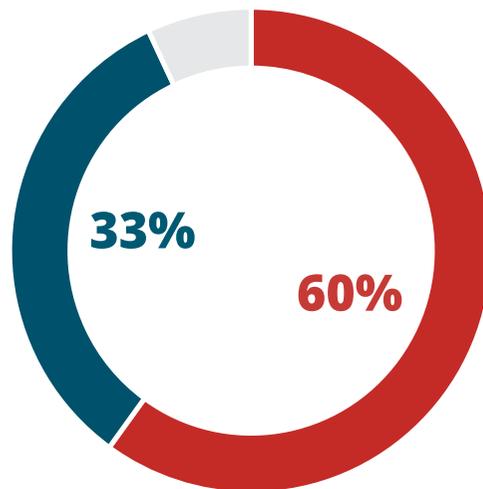
# Report card on some of the changes made by the NDIA during this time

## 3. Coronavirus hotline

Participants with coronavirus-related issues were told to call the NDIS call centre and dial 5 where they could speak to special Coronavirus teams. These newly created teams would be able to answer questions and resolve problems quickly.

- **60%** of those who did dial 5 reported that they **did not have their issue resolved**.
- **33%** reported **getting the info or change they needed**.

““ The Coronavirus team need to be better trained - they are really just the normal help desk staff - very nice but very little or no knowledge that helps during this pandemic.



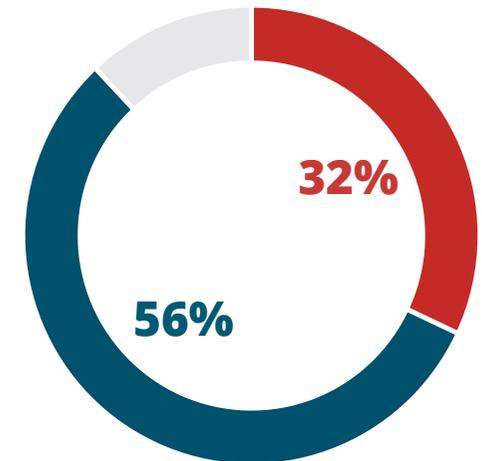
## 4. Flexibility with funds

NDIA promised greater flexibility at this difficult time - including the ability to move funds between categories.

- **32% managed to have funds moved**.
- More than **56% tried to shift money and couldn't**.

““ I put a request put in. Have been given different information from 6 staff members. No funding shifted after several weeks.

““ The increased flexibility in using funds and how support is delivered has been enormously helpful for our family during this COVID time.



# Report card on some of the changes made by the NDIA during this time

## 5. Access to smart devices

**The change in policy to allow people to purchase a smart device so they could get continue essential supports online was universally appreciated.**

Not so appreciated was the changing advice, inconsistent answers and retrospective application. The general conclusion?

“ We requested access to an iPad for telehealth. Supporting letter submitted by OT. Advised husband lost his job so we cannot afford to purchase one. Noted son was regressing. Final decision by delegate – NO. Not reasonable and necessary. Complete sessions on a mobile phone – for a child with a vision deficit?”



## 6. Pricing changes

**In recognition of the additional costs faced by providers and the uncertain operating environment, the NDIA introduced a 10 per cent increase to many NDIS services during this period.**

They also changed the cancellation policy to ensure providers would be paid if the service was cancelled less than 10 days out.

But plans were not increased to cover these additional costs – meaning some were left short at a time they could least afford it.

“We are very distressed by the 10 day cancellation. My disabled daughter has been in hospital and in critical care. She is home now and both of us need a lot of extra care. ... while she was in hospital she was being charged ... now a lot of her funding has been used and a lot of her carers are now over house and can't come and care for her as she needs.”

“ The extra 10% that providers are charging for COVID19 on top of the TTP prices are exhausting funds quickly ... if providers can charge more for supports why are the NDIA not putting extra in plans to cover this?”



# What people with disability and their families told us

## The good



We are very grateful for the difference NDIS has made to the quality of our daughter's personal development.



I would be totally lost without the NDIS. It might not be perfect or running as well as it could be but without it I would be in a very bad place.



I spoke with my LAC about how my budget for my support worker was going to run out and how my husband and I were going to pay for the support until the new plan came into effect. He explained we did not need to do that and he moved money from one area to another to keep it funded.



We as a family would like to acknowledge how fantastic the NDIS is and that our lives including our son's quality of life and standard of support workers are hugely better than before the NDIS.



I would like to thank NDIS for being responsive at this time. And although my services have been stopped for a while, I appreciate that one day soon they will resume. Mostly I am so much better off being a participant with the NDIS.



Thanks for making changes in the NDIS that may have helped some families that really need it.

# What people with disability and their families told us

## The not so good



Had a change of circumstance review meeting over three weeks ago. Despite the fact that her needs were high and she is at absolute risk, we're still waiting. Funding has run out as of four weeks ago.



We feel at odds with the NDIS rather than being in a partnership.



COVID has triggered a lot of trauma and feelings we had before the NDIS when we were on our own and in crisis that felt never ending trying to support our son. We were isolated, vulnerable and invisible. Thanks to the NDIS this has completely transformed but we felt precarious and still feel very vulnerable in many ways. I wish the NDIA would understand that.



The NDIS has been a fantastic help to me and therefore has removed a financial burden from my family. I will always be grateful for that. But please realise I am not trying to rip you off, but just live a life on an equal footing to everyone else. I don't want the world, just enough to keep me going. When I ask for help I am not being greedy, I really need help. Receiving this help makes me feel safe and I can stop being so scared. This means so much.

# What people with disability and their families told us

## The not so good



We really love the NDIS and believe it still has the potential to revolutionise lives. But it is very inequitable and the bureaucrats are determined to place as many obstacles as possible in our way.



I find the materials on the NDIS website to be so complex that I struggle to understand what is being said.



I have two uni degrees and a lot of the documents and language they use is confusing to me so heaven help anybody that doesn't have either English as their first language or just don't have the education or capacity/tools to jump through the hoods that NDIA insist we all do.



Over the three plans we've had so far, we have had mixed messages from different LACs about what the funding can be used for. I don't know if that's because the NDIA doesn't make the rules clear enough and the LACs misinterpret them, or the LACs need better training, or the NDIA keeps changing the rules. Either way this can leave families in uncertainty, either too scared to use the funding or wondering if they are going to be sanctioned at some point if they do...

# So what did people with disability and their families say they wanted?

As the events of the last two months have shown, this pandemic is far from over. And for many people with disability it will not be until a vaccine is found. So what people said they wanted to see change is more relevant than ever.

## 1

### **Recognition of the additional costs incurred a result of their disability and the provision of additional financial support**

Most people don't realise the additional costs people with disability at the best of times let alone during pandemic and the lockdowns. Additional PPE because they are a high-risk group; PPE for support workers, additional technology and data to attend telehealth and phone planning services, the added expense of online shopping – the list goes on. Some are born by other groups in the community but many are specific to living with a disability.

## 2

### **Clear simple communication**

People need to know what is happening, when it is happening and what the changes mean for them. They also need to know where they can go for more detailed information and where they can go for help.

Information must be provided in all accessible formats including translations into other languages, Easy Read and Auslan to make sure everyone hears the same message at the same time in the way that works best for them. And greater use needs to be made of the organisations that people know and trust to deliver this information.

## 3

### **Additional support from the NDIS**

For some this would mean additional funding to reflect their changed needs and circumstances. But for others it would be a different kind of help – help to reorganise their supports, or find additional services. Or help think of more creative ways to use existing funding when face-to-face services are no longer possible.

# So what did people with disability and their families say they wanted?

## 4

### **Greater flexibility**

People want to be able to use their NDIS funding in the way that works best for them. They don't want their funding tied up in line items or categories that they cannot use. They don't want to make phone calls or send emails or ask for reviews in order to move funds from one category to another. They just want to get on with the job of making sure they or their family member has the support they need.

## 5

### **Simpler, easier and quicker processes**

In the middle of a pandemic people need changes to happen quickly and easily. They do not have the time or the energy to make multiple phone calls, send multiple emails, check, call and follow up again and perhaps still not get an outcome. For some people who answered our survey the complicated processes and lengthy delays were exhausting and frustrating – but not life threatening. For others continued delays threatened their very health and wellbeing. It is not an overstatement to say that continued delays can put people's lives at risk.

## 6

### **Better training for LACS and NDIA staff**

Good intentions are no substitute for the experience and knowledge necessary to work effectively and respectfully with people with disability and their families. People want to deal with staff who are focused on listening rather than judging.

# The final word

We are aware that there remain many voices who have not been heard during this pandemic. The people who filled out our survey did so because they were already part of the Every Australian Counts community or they found their way to us during the pandemic. In some big or small way they were already connected to the broader disability community.

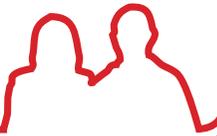
But many are not. They are alone or unable to fill in surveys or come to community forums. Their voices must be heard too. Their experiences must shape our responses. We have to find a way to make that happen.

One of the ways those voices are heard is through advocacy organisations and organisations led by people with disability. During the pandemic these organisations worked tirelessly to make sure people got the information and support they needed. Despite the vital and essential work, most did so without a lick of additional funding. We are sincerely grateful for all of their considerable efforts to make sure people with disability and their families were not – and are not - left behind.

But our most sincere and heartfelt thanks go to every single person who took the time to fill out the survey. They did so at a time when they had many competing demands. But they stopped and took the time because they wanted their voices to be heard and they wanted things to change.

**We want them to change too.**

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