



NDIS Quality and Safeguards Commission Inquiry - Submission

August 2020



Every Australian Counts thanks the Joint Standing Committee on the National Disability Insurance Scheme for the opportunity to make a submission to its inquiry into the NDIS Quality and Safeguards Commission.

Every Australian Counts is the grassroots campaign that fought for the introduction of the NDIS. It is a community of people with disability, their families and carers, people who work in the sector as well as ordinary Australians, who want to see a better and fairer deal for people with disability in this country. In the nine years since it was established, it has amassed thousands of supporters from all over the country.

Every Australian Counts didn't end with the introduction of the NDIS in 2013. The EAC community has stayed active and engaged as the scheme rolls out around the country. Our community continues to fight to make sure the NDIS stays true to its original vision and delivers on its promise to people with disability.

We want to begin our submission by acknowledging once again our support for the NDIS. We have had the opportunity to both see and hear firsthand the incredible difference it has made to many lives. When it works well, it does change lives for the better – as we always hoped it would.

But our community is also all too aware that it is not working well for everyone. Too many people are falling through the gaps, and not getting the support they need. Even those who are ultimately happy with the outcome express constant frustration with NDIS processes and policies. In short – the scheme is not yet working the way we all want and need it to. And that extends to the NDIS Quality and Safeguards Commission.

Say her name

We want to begin by acknowledging the life of Ann Marie Smith. A life that was tragically cut short in utterly horrific circumstances. Ann Marie deserves justice. We expect those responsible for her horrific death to be held accountable to the full extent of the law. For that reason, we do not want to say anything that may jeopardise the current police investigation and any subsequent court proceedings. But it is important that we begin by remembering her and saying her name.

The circumstances of her life and shocking death have prompted equal parts grief and anger from people with disability and families who are all part of the Every Australian Counts community. We are heartbroken by the circumstances of her death and we grieve her loss. But we are also white hot with anger at the system failures that contributed to her death. And we are both angry and sad at the underlying community attitudes towards disability that resulted in her death.

The circumstances of Ann Marie's death have prompted a number of inquiries, including police investigations, investigations by the NDIS Quality and Safeguards Commission, an independent inquiry by a former judge, and a taskforce and inquiry set up by the South Australian government. As well as this inquiry by the Joint Standing Committee. No doubt the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability will also examine the circumstances of her life and death. And it is absolutely right that these inquiries focus on all of the systems that failed to provide Ann Marie with sufficient support or protection.

We must look at what we need to do to prevent such a tragedy from ever happening again. Ann Marie's death is sadly not the first but it should absolutely be the last. But if we really want that to be true, we must do more than just focus on systems. Because systems alone cannot make sure people with disability are able to lead lives of their choosing, safe and free from violence, abuse or neglect. Rules, regulations, policies and systems – they all have a role to play in keeping people safe. But all the evidence shows that what really keeps people safe is the same thing that makes a good life. Community. Inclusion. Having a job. Going to the local school. Singing in the choir. Being part of something. Having friends. Being missed when you are not there.

So while there will be lots of talk in the coming weeks and months of rules and regulations and systems and protections, we don't want to lose sight of the bigger conversation that must be had about what makes a good life for people with disability. About the importance of community and inclusion. And that is something the NDIS itself could make a very significant contribution to – if it was working the way we all want it to. So while the focus of this inquiry and therefore this submission is the NDIS Quality and Safeguards Commission, we don't want to miss the opportunity to put the work of the Commission into a much bigger picture. We want to start and finish by making a plea to the Committee to help drive a much bigger national conversation about what it will take to start dismantling the barriers that prevent people from disability from being included in the community and start talking about what we have to do to make sure they have the same opportunities as everyone else.

Who is the NDIS Quality and Safeguards Commission – and what do they do?

When this inquiry was announced we put out a call to everyone in the Every Australian Counts community. We let them know how they could make an individual submission. And we also opened a page on our website where people could leave us a message, share an idea or talk about their own experience with the Quality and Safeguards Commission. That is what you will find attached at Appendix A. They are as they have been submitted to us – the only editing has been for typographical errors or information that clearly, and potentially dangerously, identifies a person or their family.

As the Joint Standing Committee is aware, we have done this for a number of inquiries. We have done it to make sure the Committee hears the experiences and ideas of as many people with disability as possible.

In the past we have received a very large number of messages and stories. This time however the number of stories, messages and submissions we received was very small. There were in fact less than 100.

We think there are two reasons for that.

The first is that this is a very difficult time for people with disability and their families. While the coronavirus pandemic has affected many people in the community, it has had a disproportionate impact on people with disability and their families. Many people are struggling to manage day to day. It would therefore be something of an understatement to say that their capacity to engage in inquiries and consultations at this time has been somewhat limited. If the committee will forgive us – to be blunt, they have much more pressing matters on their hands. We think this has had a significant impact on people's ability to contribute.

But the second reason is that we think many people with disability and their families don't even know the NDIS Quality and Safeguards Commission exists – let alone have an opinion about its operation or effectiveness.

This comes through in the stories we have received for this submission. A number of them have nothing to do with the Commission – they are in fact about the NDIS or the NDIA. That illustrates our very point – people are not really sure what the Commission does or of its relationship with the NDIS.

We talk to people with disability and their families in lots of different ways – surveys, community forums, social media, attending forums and events. From those conversations, it is very clear to us that many people with disability are unaware of the existence of the Commission or the important role it plays in the regulation and oversight of services in the NDIS.

As a result we think the Commission needs to invest much more time, energy and resources reaching people with disability and their families to let them know about their work. People need to know not just about their role in complaints but also in their regulation of providers and the oversight of restrictive practices. We don't think for example, that many people know about the Code of Conduct – or if they know of its existence, what it means for them in the context of their daily lives.

We think much more energy needs to be devoted to developing plain and simple material that speaks directly to people with disability. The Commission needs to simply and clearly explain their role, their work and what people can expect from them. But writing fact sheets and popping them on a website can never be never enough – the Commission needs to go where people are and start a conversation about their work and what it means for people. The Commission needs to do more than broadcast – if the Commission wants people to trust them it needs to engage with people and meet them where they are.

We will give you one small example. The Commission maintains a register of deregistered and banned providers. This list of providers is contained in a document on the website. The document is called “compliance and enforcement actions”. And while that language may make sense to lawyers or people who work at the Commission, it's a bit of a mouthful for everyone else. We really want participants and their families to be checking that list. Particularly self managed or plan managed participants who can use unregistered providers. They need to know. But how can they check a list if they don't even know it exists? Or can't find it on the website? Or know why they should check it in the first place?

Know your rights

As is clear from the stories and messages that follow, one of the biggest problems with the current system is that it relies on people with disability making a complaint.

But in order to make a complaint five things have to happen.

First of all you have to know that something is wrong. You have to know you have rights. You have to know you can act on those rights. And you have to know where and how to complain.

And, most of all, you have to be willing and brave enough to complain.

And being brave is no small matter. If you are no longer using a service and you want to complain that is one thing. But if you are making a complaint about a service you are still using that is an entirely different matter. It is much more difficult – and for some almost impossible.

This is particularly important for people who want to complain about supports which are essential to their daily life – for example where they live or work. These are services and supports which are not easily changed – and where the consequences for complaint may be significant.

Greater support

One of the ways to help people understand their rights and what to do if something goes wrong is through greater funding of advocacy, particularly self advocacy.

Advocacy and user led organisations can help people understand when something is wrong and what their rights are. They can also help support people through the process of making a complaint. Without this vital support complaints are unlikely to be made.

This is true of many people, but it is particularly true of people with an intellectual disability. In the stories that follow you will see that in all the cases involving a person with an intellectual disability it was a parent or parents who made the complaint.

Around the country advocacy services are already stretched to breaking point. Many have waiting lists – and some have even closed their waiting lists. Cases are triaged so that only the most urgent are assisted. There is therefore a pressing need for greater funding of advocacy to ensure people know and understand their rights and have the help they need to make a complaint.

But it would also be helpful if there was a clear and consistent system for third parties to lodge complaints on behalf of someone else. For example - in one of the stories that follows a complaint was not able to be investigated because the participant could not give verbal consent over the phone. And so the issue was not investigated and remained unresolved. But with the assistance of an advocate this issue may have been able to have been investigated.

In addition to advocates initiating complaints, there is also support from people with disability and their families for the Commission to initiate its own investigations without needing to wait for an individual complaint. In particular there is also support for the idea of the Commission carrying out unannounced visits or “spot” checks where there are concerns. A number of people note that previous state-based community visitor schemes ceased when the NDIS and the NDIS Commission were introduced. And that despite commitments by the Disability Reform Council the idea of a national community visitors scheme appears to have stalled. They would like to see these schemes revived so someone is visiting people and checking on their welfare.

The power imbalance

The stories that follow also make clear that even when people have come forward to make a complaint, their interactions with the Commission have not been positive.

The overwhelming feedback was that the Commission appeared to be “weighted” in favour of providers. People feel that the odds are stacked against people with disability and their families. They do not feel the Commission is “in their corner”. They feel the Commission too often accepts the explanations of service providers without thorough investigation. This leaves people with a terrible “what is the point” feeling.

“This leaves one feeling like the Commission acts as a shield for the Provider and that PWD’s interests are not held as a priority.”

“Many participants have felt dismissed by the commission and behaviour from the service providers have not improved.”

“The NDIS Q&S Commission encourages families of NDIS participants to make complaints but their very close association and reliance on the providers’ voices means that it is unsafe for families of NDIS participants and the participants themselves due to reprisals and retribution from the providers involved out of sight of the NDIS Q&S Commission.”

This sense of feeling like the Commission is weighted towards providers has been exacerbated during COVID19. One small example to illustrate. The Commission sent out an alert to providers in April setting out their expectations on the prevention and management of an outbreak in a service. But the matching information for participants – about what they should expect from their providers to prevent infection and manage an outbreak – did not come until many, many weeks later. What participants could expect in the face of an outbreak in a residential setting was only released in July. This information is also only available on the Commission’s website or to those who have chosen to sign up to the Commission’s newsletter. But if you do not know the Commission exists or the role that it plays in regulating providers, how would you know to sign up for the newsletter or check the website? In turn how would you know what your rights were in terms of provider behaviour during an outbreak?

Both in the stories we received for this submission and in feedback received through our other channels, people are concerned that investigations by the Commission are superficial at best – little more than “tick and flick”. They are concerned that the Commission does not have the resources or the powers to “leave no stone unturned”. Even worse – even if they did have greater powers and resource would they still behave in the same way? Many don’t have any confidence even with greater power they would investigate more thoroughly.

“Basically they are completely ineffectual.”

“The commission do not have any “real teeth” into ensuring service providers, who have been neglectful in their duty of care towards vulnerable participants (who are often totally reliant on their care), are penalised or deregistered.”

“The NDIS Commission is toothless & has no power. Made complaints & nothing was done.”

Greater choice

The stories received for this submission make one thing clear – what motivates people to complain is that they want things to be better. Sometimes they want a resolution for themselves. But more often than not they also want to make sure no one else goes through what they have been through. They want services to be better for the people who come after them.

Which explains why so many are frustrated. Both through the stories for this submission and feedback through other channels people have made it clear they feel the Commission has very few options in resolving complaints. There appear to be only two ends of a spectrum – an apology (which many perceive as nothing more than a slap on the wrist) or hefty fines and deregistration.

What many people want is more options in the middle – more work to ensure that the issue that they are complaining about is resolved. That it doesn’t happen again. That behaviour changes. That policies and procedures change. That training improves. Whatever the mechanism – they want things to get better. So they want the Commission to have more options to make that happen – and the ability to check back to make sure it actually does.

Time is ticking...

The stories that follow show that some people are happy with the work of the Commission and the outcome of their particular complaint or issue. But even those who are happy with the ultimate outcome are critical of how long things took and how many times they had to chase things up. Many people find the NDIS complex and confusing and difficult to navigate at the best of times. They find it a drain on both time and resources to manage. They describe the Commission in much the same way – that complaints disappear into a big black hole and that it takes many attempts at follow up before action is taken. And in some of the cases that follow some people said it took so long they just gave up.

So what should happen?

We would like to make seven simple recommendations. They are based on the stories and ideas that follow. They are also based on ideas and feedback that have been provided to us in other ways over the course of the last few months after Ann Marie's shocking death came to light.

1. Much more time, energy and resources devoted to genuine engagement with people with disability and their families. Not simply fact sheets on a website but much greater effort to get out to where people are and talk to them about the work of the Commission and what it means for them.
2. Radically and urgently improve information and processes so that they are genuinely accessible - for example taking a complaint from a person who used different forms of communication. And a greater commitment to co-design so information and processes make sense to those who use them.
3. Greater funding for advocacy, particularly self advocacy, so people understand their rights and know when and how they can take action. There also needs to be greater availability of support to both initiate a complaint and throughout the entire process.
4. Ensure there is a clear and consistent process for taking complaints from third parties (such as advocates).
5. Change the powers of the Commission so they can generate their own investigations.
6. Greater variety of resolution and penalties which lead to genuine service improvement.

The most important recommendation of all...

As many of the comments show, people with disability and their families are happy to see the creation of a national system of quality, regulation and complaint. They are glad to see the end of the cobbled together patchwork of inconsistent state systems.

And while some are happy with the work of the Commission, most who replied to our call out were not. Like the NDIS itself, they want things to be simpler, easier and quicker. And much, much better.

We began with remembering Ann Marie. We want to finish with a plea in her name. Those responsible for her death must be brought to justice. But that is not enough. We must critically examine every single system that was (or was not) involved in her life. Examine their limitations, their failings. And make urgent changes so people do not continue to fall through the gaps.

But even that is not enough. If we are ever to make sure that there is never again another death like Ann Marie's, we cannot solely focus on regulations and systems. They are important - but they are not enough. We need to stop pussyfooting around and start to have a genuine, meaningful and honest conversation about what prevents people with disability from being included in the community. And then decide what we are all going to do about it. **And that is the most important recommendation of all.**

Yours Sincerely

Kirsten Deane on behalf of Every Australian Counts

New banning powers strengthen protection of NDIS participants

The death of Ann Marie Smith: a shocking case of neglect, or a failure of the system?

NDIS watchdog accused of inaction

On 17 May, Smith's carer was sacked by the NDIS. On Monday, a SA Parliamentary Committee...

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