



SUBMISSION | July 2020

NDIS Quality & Safeguards Commission

Joint Standing Committee on the National Disability Insurance Scheme

Introduction

VALID congratulates the Joint Standing Committee on the National Disability Insurance Scheme for creating this opportunity to provide feedback about the work of the National Disability Insurance Scheme Quality and Safeguards Commission (NDIS Commission).

Tragically, Ann-Marie Smith is not the first person with disability in Australia to die from a preventable death under the watch of a registered disability service provider. But she should be the last. Ann-Marie Smith's horrific story reminds us that service quality is much more than passing an audit, that choice and control remain an illusion for many NDIS participants, and that the systems in place to keep people safe need an overhaul.

VALID was founded thirty years ago by people with disabilities, families and advocates who came together around a central message of deinstitutionalisation. VALID's first public action in 1988 helped to expose the horrific abuse and neglect of people living at Caloola Training Centre in Sunbury, Victoria. Since then, VALID has witnessed the closure of the state's institutions, but continues to receive requests for advocacy assistance after appalling acts of cruelty perpetrated against people with intellectual disability. Many people who left large institutions remain in smaller facilities or congregate forms of accommodation where moving out is practically impossible.

We have limited our observations in this submission to those which reflect the direct experience of our advocates and self-advocates involved in making complaints. We also commend recommendations made previously by Disability Advocacy Network of Australia and Australian Federation of Disability Organisations in their joint submission to the Community Affairs References Committee inquiry into National Disability Insurance Scheme Amendment (Quality and Safeguards Commission and Other Measures) Bill 2017, particularly the establishment of a principle on the right to independent advocacy and the importance of strengthening the statutory independence of the NDIS Commission.

We make our submission in good faith and affirm our commitment to working with the NDIS Commission to ensure that Australians with intellectual disability are provided with the highest quality support services and the best safeguarding systems in the world.

About VALID

VALID is an award-winning Disabled People’s Organisation that has been at the forefront of advocating for people with intellectual disability and their families in Victoria since 1988. VALID provides empowering advocacy support: we stand behind people to support their self-advocacy; we stand beside people to assist them in asserting their rights and seeking justice; and we stand before people who require representation to ensure their rights are promoted and defended.

VALID provides independent individual advocacy support to more than 250 people with intellectual disabilities annually, as well as self-advocacy workshops, peer-led training for more than 1500 families, self-advocacy networks for more than 300 people, 30 peer action groups in regional and rural communities, the annual Having a Say Conference with more than 1000 delegates, and runs projects in partnership with disability and community organisations and governments nationally. VALID is the Victorian Agency Member for Inclusion Australia (NCID) and a member of Inclusion International. VALID is funded via grants from the Victorian State Government and the NDIS Information, Linkages and Capacity Building program, and is not an NDIS service provider.

Vision

VALID is committed to the vision of an Australian nation in which people with a disability are empowered to exercise their rights – as human beings and as citizens – in accordance with the UN Declaration on Human Rights and the Convention on the Rights of Persons with Disabilities.

Mission

VALID’s mission is to promote and protect the human rights of people with an intellectual disability and to champion their rights as citizens to community presence, choice, respect, community participation and self-determination.

Aims

VALID aims to empower individuals with intellectual disability to:

- Exert control and influence over the decisions and choices which affect their lives
- Inform and influence the policies, processes and practices of disability service agencies, governments and other authorities
- Exercise their human rights and citizenship status within their local communities

Issues & Recommendations

VALID is an enthusiastic supporter of the role and purpose of the NDIS Commission in promoting and safeguarding the rights of people with disabilities across Australia. The NDIS Commission is to be commended for its fast work in setting up a new national complaints body, for the commitment staff at the Victorian and National NDIS Commission’s offices have shown in regularly engaging with our team on complex issues, and for taking up our invitation to be part of VALID’s Having a Say Conference in February 2020.

But, there are a range of issues which remain of significant concern to VALID regarding the operations of the NDIS Commission including

- 1 The NDIS Commission is under-resourced and cannot operate to its full potential without more staff and training. Under-resourcing leads to a focus on process instead of rights and relationships. People with intellectual disabilities cannot rely on the NDIS Commission's safeguards if staff are not able to answer every call, or if there isn't time to go out to meet the person face-to-face, or if investigations are put off for lack of investigators. This under-resourcing is most evident where there is a lack of specialist expertise and appreciation of the time needed to work with people who have complex communication or behaviour support needs as they work through the complaints or investigation process.

The Federal Government must provide the resources the NDIS Commission needs to fully discharge its responsibilities to NDIS participants and their families including more staff to take enquires and complaints, more investigators and unannounced visitors, and staff with the offices and time available to work with people who need full support to exercise their right to make a complaint

- 2 Many people with intellectual disabilities do not feel safe to complain. They are justifiably concerned about disapproval or retaliation from people they rely on for support. Or, they have made complaints before and found the process daunting or pointless. We know that there is both a real and perceived power imbalance between participants and service providers that makes complaining difficult. People will make only complaints to the NDIS Commission when they know that it is straightforward and absolutely safe.

The NDIS Commission needs a clear and published process which is adequately resourced to provide intensive assistance to people who are living in situations where complaining puts their safety or critical supports at risk

- 3 From experience we know that many NDIS participants with intellectual disabilities cannot simply pick up the phone or send an email to the NDIS Commission to make a complaint. VALID's experience of working closely with the Office of the Disability Services Commissioner in Victoria suggests that there is value in NDIS Commission staff going out and getting to know people with intellectual disabilities, their families, advocates and services providers, and that the Commission's visibility is a factor in whether or not people feel confident to make a complaint. The NDIS Commission needs to be seen in the places where people are most likely to be abused and neglected.

The NDIS Commission needs to build relationships with self-advocacy groups and advocacy organisations, and work to become familiar to people in closed, congregate and segregated services across Australia

- 4 People with intellectual disabilities have a lot to say about the choices they would make if they were in charge of their lives, their services and the systems set up to safeguard their rights. Participants and families tell VALID that they want plain information about how to spot good and bad practice, what the Code of Conduct looks like in action, where restrictive practices are happening and why, and who the problem providers are. NDIS participants are entitled to receive the information they want and need about the NDIS Commission's work in formats they can easily understand so that they can make informed decisions about their supports.

The NDIS Commission must engage people with intellectual disabilities and their advocacy organisations to co-design new ways of working with and learning from people who use specialist services, particularly people who cannot make a complaint independently, people living in closed and congregate settings, people

with complex communication and behaviour support needs, and people who have limited or conflicted decision-making supporters

- 5 In VALID's experience, NDIS participants with intellectual disabilities are too often excluded from their own planning meetings allowing decisions against their wishes and interests in their absence. Support Coordination is often underfunded despite many participants' need for full assistance with every detail of plan implementation, and service providers are relied on to act as last resort substitute decision-makers. NDIS delegates consistently deny funding for independent decision-making supports for people with no family and just one service provider 24/7. These practices create the ideal conditions for the abuse, neglect and exploitation that the NDIS Commission seeks to eliminate.

The NDIS Commission needs a more direct role in influencing the operational practices of the NDIA and Local Area Coordinators (LAC) that put participants at risk of abuse, neglect and/or exploitation

- 6 People with intellectual disability are more likely to make a complaint to a person they know, and often only in the presence of family, friends, support workers or advocates. Some people with intellectual disabilities need someone else to make a complaint on their behalf. The NDIS Commission welcomes complaints from anyone in the community, but it does not have a published process that explains how it determines the relative conflict of interest of the parties involved, or how it ensures that the participant has independent advice and support to see the complaint through.

The NDIS Commission needs to prioritise work to minimise conflict of interest in and ensure the integrity of the complaint-making process, and to ensure transparency in its own decision-making

- 7 There's no doubt that independent disability advocacy organisations play a vital role in the success of the NDIS Commission. Independent advocates help people understand their rights and responsibilities, navigate complex systems, weigh up options and make informed choices. They have intel about the quality of local services. Advocates are often the last resort for desperate whistle-blowers from disability services, statutory bodies and government. They raise the alarm when something goes wrong and work with decision-makers to solve systemic problems.

The term 'advocacy' is recognised in the General Principles of the *National Disability Insurance Scheme Act 2013 (Cth)* as having a role "...in representing the interests of people with disability...", but the relationship between independent disability advocacy and the NDIS Commission remains ambiguous.

VALID has reported cases to the NDIS Commission where the person would not consent to a complaint being made because they were unable to recognise the abuse, neglect or exploitation they were subject to. VALID also makes complaints on behalf of people who cannot consent to the complaint or the involvement of an advocate due to lack of capacity and agency.

For example, VALID received a call from a support worker concerned about a client who was required to count the same bucket of nails over-and-over again at work. The client was unable to make a complaint on her own behalf. VALID contacted the NDIS Commission's 1800-number and the advice provided to the advocate was that only the participant can make a complaint, and that because it was impossible for the support worker or advocate to know

whether the participant finds counting nails “meaningful”, the complaint would be considered illegitimate. VALID reported the advice to senior NDIS Commission staff, and a complaint was later taken from the support worker without the participant’s consent.

The NDIS Commission is yet to produce formal guidelines detailing how independent disability advocates are to be involved in supporting participants with complaints and investigations processes. VALID’s key concern is that where the advocate does not have the express consent of the person to make a complaint, the NDIS Commission has the power to determine the role of an independent advocate in the process and that the criteria the NDIS Commission uses to make these decisions is unclear. The result is that participants who cannot make a complaint, and are subject to abuse and neglect, have more limited opportunities to exercise their legal capacity including having access to independent representation, and that their advocates are unable to determine whether the processes taken by the NDIS Commission in a particular case are fair and equal. Freedom from abuse and neglect is an entitlement and should never depend on a signed consent form.

The NDIS Commission must work quickly to establish an agreed formal protocol with independent disability advocacy organisations that clarifies the roles and relationships, including specific processes for the involvement of independent advocates for people who cannot provide consent