



Rights, Safety and Quality - *Voices of advocacy*

Disability Advocacy Network Australia Submission to the Disability Royal Commission

December 2022

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About DANA

Disability Advocacy Network Australia (DANA) is the national peak body for around 80 independent disability advocacy organisations across Australia. Our goal is to advance the rights and interests of people with disability by supporting our members in their targeted advocacy as well as engaging in systemic advocacy on a national level to further these objectives. DANA works to a vision of a nation that includes and values persons with disabilities and respects human rights for all.

Independent advocacy agencies address the advocacy needs of those people with disabilities who are more likely to be vulnerable to abuse, neglect and/or breaches of their fundamental human rights. They do this through a variety of delivery models that include systemic advocacy, legal advocacy, individual advocacy support by paid professional advocates, citizen advocacy using trained volunteer advocates, self advocacy development and support, and family advocacy development and support.

DANA's input can provide insight into the myriad of human rights problems faced by people with disabilities in contemporary Australia. Our membership is comprised of advocacy organisations that work to protect the rights and interests of some of the most disadvantaged and marginalised people with disabilities. To manage within limited funding environments, advocacy services often prioritise clients with cognitive impairments, communication barriers, complex needs, those with experience of institutionalisation, abuse or neglect, and those without strong networks of support from peers, family or friends.

Executive Summary

In their daily work, disability advocacy organisations work to safeguard the human rights of individuals with disability to be included in the community, live free from violence, abuse neglect and exploitation and access quality supports. Disability advocates possess extensive insights about the strengths and shortcomings of Australian mechanisms designed and implemented to promote safety and quality across a range of service systems used by people with disability. In DANA consultations, they have spoken at length about the barriers people with disability experience when accessing or interacting with complaint mechanisms, whether this is fear of retribution or other consequences of making a complaint, lack of rights awareness or effective complaints responses, or segregation and isolation from the community.

Disability advocates also identify inconsistencies and gaps in safeguarding frameworks applied across Australia. Through the nature of their work, they are generally more exposed to the characteristics of poor quality disability services. Yet they can describe and articulate the features of high quality services, including that they:

- give attention to the needs, will and preference of the individual with disability;
- support autonomy, control and choice;
- train staff in human rights principles;
- recognise 'behaviour' as communication;
- strive to be trauma-informed;
- lead cultural change at all levels; and
- ensure access to independent advocacy and support to make complaints.

Independent advocacy organisations themselves can play a vital role in strengthening informal safeguards and developing the personal capacity of people with disability to safeguard themselves, including through their work building human rights awareness and supporting self-advocacy skills. This can also occur through peer support, supported decision making and other forms of education and capacity building.

Generally, efforts to uphold independence, choice and control in service contexts contribute to the quality of services and safety of people with disability. Advocates have observed a range of service settings operating with limited or insufficient oversight or active monitoring for signs of abuse, violence, neglect or exploitation of people with disability. To improve the current arrangements, advocates believe ensuring the accessibility and integrity of complaints mechanisms and improved access to independent advocacy for people with disability at risk are vital challenges.

These improvements require ensuring the independent advocacy sector is resourced, networked and supported to meet the needs of all people with disability. There also needs to be cross-sector efforts to focus on human rights across all service settings and government investment in disability rights awareness and education across the community. Particular

attention must be paid to identifying and reaching people who need additional supports, including those who face communication barriers and people who have limited or no informal support networks. To address intersectional disadvantage and discrimination, improvements must also meet the specific needs of groups who have been identified at higher risk of violence, abuse neglect and exploitation, including First Nations people with disability, culturally and linguistically diverse communities, children and young people, non-binary people, women and girls.

[How to navigate this document](#)

This document collates a great deal of material, and it is not intended that all readers will follow the document from beginning to end. To make it easier to find content on topics of interest, you may wish to use the hyperlinked [table of contents](#) above. You can use the link in the footer of each page to jump back to the table of contents quickly. There are also other hyperlinks included throughout the document for you to refer quickly to other relevant sections. Additional material is included in the appendices, including [Appendix A: Advocates voice their ideas for improvement](#).

Capturing the voices of advocacy

During the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability ('Disability Royal Commission' or DRC), DANA's very small team has been engaging with the advocacy sector on the delivery of DRC advocacy support by a number of National Disability Advocacy Program (NDAP) funded organisations since 2019, and also providing support to other advocacy and Disabled People's and Family Organisations to inform and engage people with disability, their family members and supporters in DRC processes.

DANA hopes to amplify the voices of advocates on the ground throughout the course of the DRC, to ensure the stories of people with disability that advocacy organisations work with can be heard.

To this purpose, DANA collaborated with the DRC Community Engagement team to hold a series of jurisdiction-focused online workshops to discuss the cross-domain topics of restrictive practices and segregated settings. Beginning in October 2020 and concluding in March 2021, DANA held workshops in each State and Territory. DRC staff from the Policy and Community Engagement teams were in attendance for these workshops. Commissioner Alistair McEwin and other relevant staff have also attended several workshops. In April 2021, we held two cross-jurisdictional 'solutions-focused' workshops to delve deeper into the prevention of violence, abuse, neglect and exploitation and the recommendations that advocates would like to see made.

In late 2020, DANA also held a series of weekly online discussions for interested advocates. The “Advocates Zoom In On...” discussions aimed to capture advocacy insights, perspectives, stories and examples in relation to different topics of relevance to the DRC, including one specifically focused on “Safeguarding rights and wellbeing”. Simultaneously, we also offered advocates the opportunity to provide written input on these topics through online surveys.

DANA organised these online workshops and discussions because we were concerned that the overstretched capacity of the advocacy sector during the DRC timeline will result in these insights not being captured by DRC processes. We hoped to create specific spaces and opportunities for busy disability advocates to contribute their memories of past cases and other systemic insights to the DRC evidence base and allow advocates to meaningfully engage in the process of informing recommendations and reforms.

Listening to advocates speak and give examples during these online discussions has underscored how knowledgeable advocates are about the experiences of people with disability interacting with complex and flawed systems of service delivery and reporting and complaints mechanisms. This document collates the de-identified direct quotes of advocates under themes relevant to this expansive topic of “safeguards and quality services”. Its structure is influenced by the phrasing of questions and topics identified in the DRC Issues paper on ‘Safeguards and quality’, published in November 2020.¹

The following excerpts reflect just a fraction of the insights and experiences of advocates and independent advocacy organisations in their work upholding the rights of many individuals with disability.²

Online workshops and discussions

Participants in the online workshops and discussions (largely disability advocates or advocacy managers or executive officers) were encouraged to share their insights, observations, stories and case studies. The discussion questions each week included opportunities to share perspectives on what recommendations advocates would like to see being made by the DRC, in relation to the topic in focus.

Identifying details have been removed from the excerpts included below. Advocates are only identified by the State or Territory in which they work. Participants were informed that sessions would be recorded to capture their insights and observations. Live captioning of the workshops by [The Captioning Studio](#) was arranged by the DRC. Live captions of the “Advocate Zoom In On...” discussions were provided by [AI-Media](#). Care has been taken but errors may exist in the transcription.

¹ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*.

² This document also includes relevant quotes from past consultations by DANA, including from surveys conducted in relation to the Quality and Safeguarding Framework in 2015 and on National Disability Strategy progress on outcomes in 2014.

We remind readers that the quotes below are largely transcribed from the speech of advocates during group discussions and this has influenced syntax and flow of expression. We have found these direct quotes of advocates to be insightful, thoughtful and compelling, so we have chosen to capture and present their perspectives, largely, in their own words.

Acknowledgements

DANA would like to acknowledge the Traditional Owners of the various lands around Australia from which advocates participated in these virtual meetings and pay our respects to Aboriginal and Torres Strait Islander Elders, past, present, and emerging.

DANA would also like to acknowledge the time and generosity of participating advocates from a diverse range of advocacy organisations around Australia, and the funding of the Australian Government Department of Social Services for DANA to provide DRC systemic advocacy support. Visit www.dss.gov.au for more information.

DANA's small team would like to express our appreciation and support for the systemic policy work and expertise of our fellow Disability Representative Organisations:

- [Australian Federation of Disability Organisations](#)
- [Children and Young People with Disability Australia](#)
- [First Peoples Disability Network](#)
- [Inclusion Australia](#)
- [National Ethnic Disability Alliance](#)
- [People with Disability Australia](#)
- [Women with Disabilities Australia](#)

We encourage the DRC to consider their submitted and published statements of relevance to these topics. We also encourage you to refer to the responses and other submissions of disability advocacy, peer support and representative organisations around Australia,³ including those by People with Disability Australia (PWDA);⁴ People with Disabilities WA (PWDWA);⁵ and Leadership Plus (in Victoria).⁶

³ DANA's website links to available [Submissions by advocacy organisations](#) that have been submitted to the DRC.

⁴ People with Disability Australia (2021) *Safeguards help marginalised people with disability - Submission responding to the Disability Royal Commission's Safeguards and Quality Issues Paper*

⁵ People with Disabilities WA (2021) *Submission – Issues Paper: Safeguards and quality*, pp27-30.

⁶ Leadership Plus (2021) *Unsafe at any speed – A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Re: Safeguards and Quality*, pp5-8.

Section 1: Independent Advocacy - safeguarding rights and promoting quality

There is a particular focus throughout this document on the crucial functions performed by independent advocacy in enhancing quality in services and supports, and in safeguarding the rights of people with disability in complex systems.

*“Advocacy services may be preventative in that they can enable adult at risk to express themselves in potentially abusive, or actually abusive, situations. Equally, their presence in enabling people to express themselves in other situations (for example when their needs are being discussed or at times of transition) may contribute to building confidence more generally and hence be preventative.”*⁷

Independent advocacy plays a vital role both in protecting the rights of individuals and in ongoing systemic quality assurance and improvement.⁸ By scrutinising and challenging the disability service system, advocacy adds to its accountability. Access to independent advocacy fosters greater wellbeing, autonomy and community participation and other positive outcomes for people with disability, and thereby strengthens safeguards against abuse, violence and exploitation.⁹

[Independent advocacy is the] crucial, critically important part of the whole process of protecting, safeguarding and helping people with disability who are being abused or have been abused to make a complaint or work their way through the system and in the first place to protect people against some of the things that happen.

DANA CEO Mary Mallett¹⁰

[Advocates] “inform people about their entitlements and empower them with all the information they need to make informed decisions. They ‘bridge’ between the service and the people, and bring a specialist understanding of the systems and processes. They help people understand what their entitlements are, what they can expect, and how to navigate

⁷ Alison Faulkner and Angela Sweeney (2011) Social Care Institute of Excellence Report 41: [Prevention in Adult Safeguarding](#) (Reviewed May 2014).

⁸ Research literature indicates that advocacy improves the attitudes of professionals in service delivery systems: Alison Macadam, Rich Watts and Rob Greig (2013) *Impact of Advocacy for People who Use Social Care Services*, NIHR School for Social Care Research, London School of Economics and Political Science.

⁹ See Anne Daly, Greg Barrett and Rhiân Williams (2017) *A Cost Benefit Analysis of Australian independent disability advocacy agencies* – Report commissioned by Disability Advocacy Network Australia, August 2017, Canberra: available at [Publications | Disability Advocacy Network Australia](#); Deloitte Access Economics (2013) *Identifying and measuring the outcomes of advocacy*- Report commissioned by ACT Disability, Aged and Carer Advocacy Service

¹⁰ Mary Mallett quoted by the Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, Final Report 188.

the system and monitor quality assurance. They stand up for, and with, people who are vulnerable. It's sad that we even need such a role and in an ideal world we wouldn't but unfortunately this isn't an ideal world and the role of independent advocacy is essential.

QLD Family member of a person with disability¹¹

“Independent advocacy, that is advocacy that is in no way attached to services provided to people with disabilities, is one of the most powerful safeguards available. Being free of conflict of interest, independent advocacy can, as it should, focus on the needs of the vulnerable person/people. It can also seek out people who are vulnerable and would otherwise not access any advocacy or complaints mechanisms. We know that the very presence of advocates in the lives of vulnerable people makes a difference to how service staff respond. They often become more diligent and careful about meeting the person's needs. In some forms of independent advocacy, the advocates become familiar with the vulnerable person to the extent that they can respond with relevance and potency to issues as they arise and even help avert crises. Independent advocacy can improve the positive impact of services by ensuring that services are targeting the real needs of people (being relevant) and reducing the over servicing of people also (ensuring a developmental focus as the person grows in knowledge and competency).”

SA Advocate¹²

“Advocacy has a role in supporting people with disabilities to know their rights, and to ensure that they can make and pursue a complaint if an issue arises. People with disabilities are almost always abused/or and neglected by someone they know, and often by someone on whom they might rely [on] to support them to make a complaint (e.g. a group home staff member may abuse a client and may also be the only support person available to assist the client to make a call to Police), ensuring that a complaint is never made.”

VIC Advocate¹³

“[Independent advocacy] safeguards the safety and wellbeing of people with disability because they can learn their rights, have a voice to assert them, and to where and how to complain if necessary. This will improve the quality of services they receive by the services receiving feedback and external funding bodies becoming aware of complaints about the provider.”

WA Advocate¹⁴

¹¹ DANA's 2015 *Quality and Safeguards* survey - Response from QLD Family member of a person with disability

¹² DANA's 2015 *Quality and Safeguards* survey - Response from SA Advocate

¹³ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

¹⁴ DANA's 2015 *Quality and Safeguards* survey - Response from WA Advocate

“Independent advocates work wholeheartedly for people with disability. They are not beholden to the interest of their employer (e.g. service, accommodation). This inherent quality of an independent advocate [distinguishes] them from other service providers. Independent advocates have special skills to successfully engage services and resources and pave the way to access these resources and services.”

NSW Advocate¹⁵

“...at times we are first responders and already engaged with somebody for a completely separate reason, and as you build a better relationship with them, or information comes to light... I have had to be in situations where this is the first time they have had a conversation with someone, then having to be strategic about what to do with that information.”

SA Advocate¹⁶

“...over the years the people I've worked with have said, how important it was knowing we were available and unconditionally on their side for as long as 'it took'; we are able to intervene, call it out for what it is, and support people to constantly have their services improved or changed. Advocates...can be heard when the person with the disability is not being listened to.”

VIC Advocate¹⁷

“It allows people with disability to understand their full entitlements and not be pushed into making decisions that do not fully enhance their life, or that will put them in harm's way. Very important for all to have this essential access.”

QLD Family member of a person with disability¹⁸

“Once trying all avenues, being bullied, abused and discriminated, it's time to find an advocate, just knowing that safety net is there is a life saver, not an exaggeration for some, an actual life saver just to get through the issues we are faced with all the time.... listen intently, treated as an individual, validated, supported, follow up, no judgement.... Helps give encouragement, ideas, tools to try a new issue on our own. Builds self esteem.”

WA Person with disability¹⁹

¹⁵DANA's 2015 *Quality and Safeguards* survey - Response from NSW Advocate

¹⁶ SA Advocate, "Advocates Zoom In On... *Advocacy & Abuse Prevention*", December 2020 Zoom discussion

¹⁷ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

¹⁸ DANA's 2015 *Quality and Safeguards* survey - Response from QLD Family member of a person with disability

¹⁹ DANA's 2015 *Quality and Safeguards* survey - Response from WA Person with disability

Section 2: Barriers to making complaints²⁰

DANA has long argued that accessible and effective systems of complaints management, escalation and resolution are critical to the protection of individuals with disability.²¹ The experience of the advocacy sector is that well-functioning accessible complaints mechanisms can effect change and improvements in the disability services system and other systems. However, far too often the capacity to pursue a complaint through existing mechanisms has been hampered by inadequate access to independent advocacy or even a lack of awareness among consumers of their right to complain.²²

DANA's 2015 consultation with advocates, people with disability, carers, family members and support workers found that many consumers experiencing poor quality supports and/or unsafe environments often struggle to make complaints, or choose not to even try, for a range of factors. See [Appendix B: Barriers to making complaints](#).

Existing complaints processes have often been ineffective in protecting individuals with disability who have lodged a complaint, leaving people vulnerable to intimidation and abuse. The power imbalance that exists between the consumer and service provider prevents people from pursuing their rights, instead resorting to finding ways of surviving within the system.²³

“power imbalance, communication and complaint management is difficult, unfair, dismissed, can't cope with it, no justice, reoccurrences, new staff having to learn again, continuous mistakes” “waste of time, no feedback from the safety and quality commission, behaviours of the service continue, no accountability”

QLD Advocate²⁴

“The ability to communicate effectively is the largest barrier I have seen. Often they can be unheard, dismissed, misdirected, actively ignored or completely misunderstood.”

QLD Advocate²⁵

²⁰ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p7. Question 9 asked: “What barriers do people with disability face when making a complaint and what will help address these barriers? We are interested in hearing about complaints processes across a range of services and areas of life.”

²¹ For instance, DANA's 2011 *Position Statement: NDIS Complaints and Review* and 2013 *Federal Election Call to Parties*.

²² The Senate Community Affairs References Committee (2015) *op. cit.* 194-197.

²³ Bill, H. (2015) *A Missing Piece: The need for independent advocacy in the NDIS Quality and Safeguarding framework* (Honours Report) - See [Attachment A](#).

²⁴ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

²⁵ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

“...with regard to the justice system and juvenile justice, sometimes it's confidence, it's education of the parents and they're up against the justice system. They may put in complaints, but they don't get answers. They don't know how to follow it up. And it's having the confidence and education to take that on and the capacity and that's a major issue.... previously they haven't been successful, so when they've tried it on their own, it hasn't worked. Then they come to us.

Or with one of the cases it's quite complex, all this has come out two years' later, so then we help them apply for freedom of information and they're bringing a case now. But previously, you know, there's complex family circumstances, maybe one parent families. They don't have the time, they don't have the capacity or the education or the confidence to keep challenging the system to follow up the complaints or they feel they're being fobbed off and they don't know where else to go. And then the other side is retribution. If you put a complaint in, will the client suffer?”

WA Advocate, November 2020 Zoom workshop with DRC

“Many people who are subject to RPs [Restrictive Practices] have significant intellectual disabilities and cannot speak up for themselves. If their family/SIL [Supported Independent Living] provider all want RPs to make life easier, the person subject to RPs needs an independent advocate to speak up on their behalf as their interests do not always coincide with the interests of those caring for them”

QLD Advocate²⁶

“I think there's an assumption that if the provider is registered, they are qualified and people don't challenge them”

SA Advocate, April 2021 Solutions focused workshop with DRC

[Fear of retribution or other consequences](#)

As Reinforce Self Advocate Colin Hiscoe articulated at the Living in Group Homes hearing in December 2019:

“I think you need to get there into the group homes. The biggest problem might be that no matter what you do, the people there are going to be really scared, they're going to be afraid, they're frightened of retribution, they're frightened of being in trouble, they're frightened of being hit, whatever, and they're really scared.”²⁷

²⁶ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

²⁷ Hearing on Living in Group Homes - Transcript of proceedings - Day 4, Thursday 5 December 2019, Melbourne.

Advocates are very mindful of the genuine fear of retribution or reprisals that make it difficult for people with disability to speak up and voice complaints or report abuse. They are also aware of the fear of other consequences that may arise from voicing a complaint including facing legal processes, changes to relationships, or loss of community connections.

Fear as a barrier was frequently articulated by disability advocates and other respondents to the 2015 survey - see [Appendix B: Barriers to making complaints](#).

“It's too hard. There might be retribution. I could lose the service all together. I will hurt people's feelings. The police won't believe me. Mum or Dad will be upset with me. In a small community, everyone will hate me for rocking the boat...”

VIC Advocate²⁸

“Without independent advocacy there is a lack of reporting back to the client and the client is also vulnerable to reprisals by individual support staff if the quality of service directly relates to them.”

WA Advocate²⁹

“I just wanted to bring it back to that setting where the service providers are saying that for this to be financially viable, we have to provide you with all of your supports and your support is tied to your accommodation and I guess there comes that risk of ‘if I piss off my service provider, I'm going to lose my house, you know, so I will put up with being potentially abused, neglected, exploited, having restrictive practices put against me because I'm really worried about my housing and where I'll go or if I can find another place in another home –’

[Colleague: “Or I'll lose my community. It's not just that they will not have a home because even if they are moved to another home because they're unhappy with the service provider, they've lost their community and it can be very challenging for people to rebuild that and it can be very challenging for people to get to that if they've moved”]

WA Advocates, October 2020 Zoom workshop with DRC

See also [Examples - Fear of retribution or reprisal](#) below.

Staff of service organisations may also be influenced by fear of reprisals in deciding whether to take action about mistreatment or abuse:

²⁸ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

²⁹ DANA's 2015 *Quality and Safeguards* survey - Response from WA Advocate

“We have represented whistleblower clients (support workers within group home/residential facilities) - who have also experienced extreme pressure, bullying and intimidation by their employers when bringing these episodes of malfeasance and neglect to their attention. Most fear for their jobs and other reprisals in coming forward to share their story.”

QLD Advocate³⁰

Lack of rights awareness

Advocates stressed the lack of awareness of human rights and the right to complain:

“...the majority of vulnerable people are unlikely to complain... Some may have no mechanism for complaining due to limited communication options or severity or complexity of their disability. Some may be complaining by way of behaviour which is not being listened to effectively. Many are unaware that they can complain or that the way things are is not the way things should be. Those few people who can complain often have difficulty negotiating the bureaucratic and limited complaints processes available to them.”

SA Advocate³¹

“I think many of them are so institutionalised. They wouldn't know that they have a right to complain. They wouldn't know where to go to. I mean, some work has been done in that area to improve it, but there's a long way to go, and that's why advocates are so essential to the whole process.”

ACT Advocate, October 2020 Zoom workshop with DRC

“There is a case that I'm working on to take to the Royal Commission. A person in a group home who had no outside supports. She had nowhere to speak up for her. So that capacity first of all to recognise that she was being treated badly, and secondly, what to do about that.

Like... not even knowing who to speak to about that. That is part of the failure in the system, there is a reliance on people who don't necessarily have the skills and resources and understanding of those issues to speak up for themselves. That is why advocacy is so important.”

VIC Advocate³²

“I think people with a disability don't talk, they're not given the chance to have input into little things... how do they stand up to people and say we've been abused or neglected or exploited

³⁰ QLD Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

³¹ DANA's 2015 Quality and Safeguarding Survey - Response from SA Disability advocate

³² VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

when they're too scared to say 'I want to have that support worker' and they're told no. If they put in something to say 'this has happened', who's going to listen to them?"

TAS Advocate, November 2020 Zoom workshop with DRC

"...I don't think that people [with disability] do understand that it is restrictive practices, what a restrictive practice is or even really understand that word. If it's difficult for service providers and other people to actually figure out what is and is not a restrictive practice, I don't know how we expect people to understand that..."

SA Advocate, December 2020 Zoom workshop with DRC

"...people with disability being involved in decision making at all levels. Yes, it's a significant concern amongst the people that I work with that this doesn't occur and the focus on that. Particularly from our ATSI [Aboriginal and Torres Strait Islander] worker, concern about the lack of understanding around some forms of abuse, particularly financial abuse, so yes, abuse occurring without intentionality."

VIC Advocate, April 2021 Solutions focused workshop with DRC

Where it is normalised in service settings, family members and other supporters may also have trouble identifying what counts as neglect or violence:

"I have had a brother not realising that his sister being hit by another resident was a big deal. He called about other issues."

VIC Advocate, February 2021 Zoom workshop with DRC

[Lack of effective complaints responses](#)

Advocates also explained how inadequate and unsupportive mechanisms often minimise or frustrate the attempts of complainants with disability to secure outcomes or effect change. This lack of effective responses when complaints are voiced has had a deterrent effect on people with disability or their supporters choosing to voice their complaints through that mechanism or process in future.

"I think in the situations where people are very active in complaining and speaking out against restrictive practices, even though they may be able to go through the motions, so to speak, of being granted review hearings for SACAT [South Australian Civil and Administrative Tribunal] and that sort of thing, I think it's really difficult for people who in that setting have had a proven "mental incapacity" and especially if there's a psychiatric element to that they may be able to go through that process of complaining, but I think it's very difficult to actually be heard in that setting. So for someone I'm thinking of specifically, that experience just meant that the restrictive practice was viewed as the support trying to hurt them and so that

created more problematic situations and that person was very persistent in trying to overturn those orders and trying to be heard, but the systems themselves weren't on board with that."

SA Advocate, December 2020 Zoom workshop with DRC

"...look, we have some people who make complaints all the time about everything who are very comfortable with complaints processes, who know that they do have some rights and are very, very happy to exercise those rights. We have others who would never make a complaint and who need constant support, who find the processes, I mean, complaints mechanisms, are not necessarily friendly for people from non-English speaking backgrounds. So our clients are mainly people who don't have English as a first language. So having a sign up on the wall saying "you can make a complaint" is not really all that helpful, or saying that you have to get a complaint in writing is not all that helpful.

It depends on... for us it's very much linked to families. Some families have high levels of English literacy and have had a lot of engagement with services over a long period of time and are pretty comfortable with using complaints processes. We've got other families who might have huge issues."

NT Advocate, November 2020 Zoom workshop with DRC

"Complaints to the Quality and Safeguards Commission, you know, have gone nowhere and in one case we've even had to complain about the Commission because there are no outcomes and no tangible sort of investigations, you know. Even on our advice, sort of saying this is what you need to look at and this is what we want, you know, to be looked at, it's just like a chat. It's pretty toothless. I don't know if it's because they haven't got the resources or what it is, it might be."

VIC Advocate, February 2021 Zoom workshop with DRC

"I've known some people that I'm supporting and their families just choose not at all to even submit a complaint to the [Quality and Safeguards] Commission because they have heard about their reputation of not having teeth."

VIC Advocate, February 2021 Zoom workshop with DRC

"The particular service that had a mass lot of evictions, I managed to get the same Quality and Safeguards operator investigating the complaints across the board. The trouble is, their jurisdiction is incredibly limited and you have to have made a complaint, the service has to have failed to adequately resolve the complaints. And because it's all tied to market-based registration, you've got to find an issue where you can escalate to a complaint.

If they are just being obtuse, that is not complaint-worthy. In one situation the only reason we managed to get it to a substantiated complaint, was because they were refusing the person responsible restrictive practices data when she was the appointed guardian for restrictive practices. But if they are just ignoring you, it's a lot harder to get that to a formal complaint that they haven't responded in the timeframe, and then moving it on. It is very bureaucratic.

So you're looking... and you shouldn't have to look for your technical way in. It should be just, "This is not right, we need to do something about it."

NSW Advocate³³

Some advocates described a lack of any real or effective remedies to make providers accountable to relevant service standards:

"...you have to train the staff, but the other real problem is that service providers know that they're not accountable. The NDIS Quality and Safeguards Commission does not have powers to act against service providers in individual complaints and the New South Wales Ageing and Disability Commission, who is now getting a function to what they call oversee restrictive practices, also does not have powers to make any penalties or findings against service providers in individual cases. So we now have two regulatory authorities that appear to be regulating but, in actual fact, do not have any powers against service providers in individual cases to stop things. I am not talking about the obvious things like assaults and sexual assaults and things like that. I am talking about the day-to-day things, like restricting diets, closing doors, not letting them go out into the community. What we really need is tribunals that you can go to that will listen to the complaints and deal with them in a very short period of time, and we haven't got it."

NSW Advocate, March 2021 Zoom workshop with DRC

(See further commentary on the Quality and Safeguards Commission in Section 6: [Independent monitoring and oversight](#).)

Another advocate pointed to highly administrative and legalistic processes excluding many people with disability:

"I think there are real limits to the legal process. Not many people could actually manage that. It actually requires quite a lot of resources for individuals. Often in my experience, just working in advocacy, people have to have pretty organised sort of lives and have a sense of investment in the mainstream, have capacities to organise paperwork. I just think that we live more and more a legalistic system. I think that's one of the problems. We need to have

³³ NSW Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

a way of promoting exchange, of conversation, communication, that's not about all this administration. I think we've got into a world of technology and phenomenal legal wrangling actually, which I think is actually problematic for many people."

NSW Advocate, March 2021 Zoom workshop with DRC

Segregation of people with disability away from community

Another major barrier to complaints or to the reporting of abuse, violence or neglect, is the fact that many people with complex and significant disabilities continue to live institutionalised and "shut in" lives in segregated settings such as group homes, boarding houses, hostels or aged care homes. This is particularly acute where a provider delivers all support for an individual, eliminating any opportunity for person with disability to seek help from someone who is independent of that provider.

"Many services have 'whole of life', so [people with disability] don't have any opportunity to make a complaint...can list the services who have whole of life, and who go to the planning meeting with them, so no option of changing services in the face of their SP [service provider]."

TAS Advocate, November 2020 Zoom workshop with DRC

"...in terms of what we found, just getting access to the justice system can be frustrated by, particularly in closed environments such as group homes, a particular mechanism of internal investigations. If the perpetrator of the violence or abuse is a group home staff, there is a lot of, 'we investigated ourselves and found nothing wrong'. Often without external support, which can be physical in terms of having access to a phone to report, or going to a police station, they can't further escalate to the justice system and the support providers are unlikely to provide support to do themselves in."

SA Advocate³⁴

"I have seen it frequently in residential aged care facilities, so I'm talking about older people who have disabilities, and I think the common denominator tends to be people who are very isolated who don't have an advocate or a family member or someone close to them looking in on them and checking that things are OK. That's where I believe, abuse tends to flourish or can flourish."

ACT Advocate, October 2020 Zoom workshop with DRC

³⁴ SA Advocate, "Advocates Zoom In On... *Criminalisation*" October 2020 Zoom discussion

“I was just going to extrapolate on the idea of getting rid of segregated settings. By having them in the first place you send a clear message to everyone else in community that people don't belong, that they're not good enough or somehow they're different, inferior or problematic. So if we want to have higher scrutiny, more protections for people from abuse, violence, neglect and exploitation, then they need to belong in community. When you belong in community and you're well known in community, you have more eyes on you and potentially more relationships.

Even if you don't have relationships and you're known, at least you have eyes on you and people will step in if they see something untoward or report something untoward. Not everyone, let's face it, people stand by when anyone is experiencing something horrible at times, but all the while you're closed away, hidden away or even out in groups you're someone else's responsibility. People assume that if there's a group of people with disabilities and a group of workers with them and there's a kerfuffle or somebody is upset, people look away. They just assume that they'll be taken care of. But if a person is walking around the shops or the community with one worker and there's a kerfuffle and someone is upset, people might stop and ask, "Are you okay?", intervene, check out what's going on and see if there's something bad happening. That won't happen in segregated settings.”

QLD Advocate, December 2020 Zoom workshop with DRC

Section 3: Inconsistency and gaps in safeguarding³⁵

During the consultation on the Quality and Safeguarding Framework, DANA's 2015 survey collected people's thoughts on the effectiveness of different complaints mechanisms in their jurisdictions.³⁶ Since then, there has been considerable change in the safeguarding arrangements including in frameworks for oversight of restrictive practices.

Some advocates noticed marked improvement in the introduction of the Quality and Safeguards Commission in their jurisdiction, such as Tasmania:

“I also think it has changed a bit in Tassie now we have the Quality and Safeguards Commission. There is a clearer process for organisations and for support staff. But before then I found I had a lot of support workers and people who worked in organisations contacting me to follow up to make sure they were following the right process to report abuse, neglect and violence. And that people had had that independent voice. I think it's happening better now, in some ways, that we have got the Quality and Safeguards Commission here in Tassie.”

³⁵ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p6. Question 5 asked: “What challenges are presented by the different safeguarding approaches used across Australian jurisdictions and across different types of services?”

³⁶ See some of the responses presented in [Appendix B: Barriers to making complaints](#).

"...also the pressure from organisations, because they might be aware of what they have to do to report, and they seem to be getting us in earlier. That's my experience anyway, since the introduction of the Quality and Safeguards Commission."

TAS Advocate³⁷

However, many advocates had observed continuing problems and even deteriorations in safeguarding during this transition:

"There isn't an understanding among service providers that the person has a right to have independent people in there. Certainly in NSW, since they got rid of the community visitor, there's no teeth behind any of the compliance frameworks to back that up."

If you suspected abuse prior to Quality and Safeguards rolling out in NSW, you could call the Ombudsman, give them the factual basis for your concerns, and by and large if you knew what you were doing and you could highlight the right kind of thing, you could get a Community Visitor there within two weeks who had a legal right not to be blocked. They would identify the issues and say yes, there is something wrong here, this person definitely needs an advocate... and you didn't have to go through the guardianship process."

Quality and Safeguards is mediation. It's great if you have some kind of service agreement dispute with your provider and the outcome you want is for them to do something. But it really, really doesn't work in the cases of abuse."

I had people that in lockdown, nobody set eyes on for three months other than the group home provider. I know a number of them were subject to physical abuse during that time. But when it is a service that doesn't keep records of incidents, proving that is virtually impossible."

NSW Advocate³⁸

"One of the big gaps is soft entry block-funded things. NDIS covers the big headline support needs, but a lot of the soft small stuff is gone. And some of that is what provided the safety networks around people."

There were a lot more small programs at community centres and things that you could refer people to, to build their unpaid networks around them. That's largely gone. And even NDIS-funded services that used to be more wraparound, that discretion with how they apply supports has gone."

³⁷ TAS Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

³⁸ NSW Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

So even services that used to provide some of the buffer and protective mechanism to more vulnerable clients I work with, are no longer able to do it because it's a unit cost system. There are lots of advantages to individual funding, but it has removed a lot of the undocumented safety nets that were there... that in a block funded system would go, that person is really vulnerable, I'm going to spend a bit more time on that. If there is not the allocated hours in the system, that just doesn't happen.

The other thing that I've noticed that makes advocacy harder is when it wasn't a competitive environment it had more services going 'this isn't quite right, maybe I should refer that person there,'... that kind of linkages and discussion work that has gone. A lot of service providers I have worked with in the past that were really good at picking up and referring in a proactive way, that is just not happening, because everything is staying in house and you are only doing exactly what you can claim for."

NSW Advocate³⁹

(See [Section 5](#) for more discussion of the need for strong capacity building programs, including self advocacy, supported decision making, peer support, leadership and other skill development activities.)

"What I found is that even service providers who may once upon a time have understood the role of advocacy, a lot of them have assumed it has disappeared with NDIS. I'm seeing a lot of the campaigns about it being at risk... There's also been a lot ... I guess, the changes around Quality and Safeguards and the changes to how restrictive practices are managed with the transition to the National Standards [for Disability Services] has also seen a lot of confusion and cover-up, for lack of a better word, in some of the more institutionalised group home providers, and a lot of just going to ground because it's a business now. And you've got to lock that business in."

NSW Advocate⁴⁰

Several Queensland advocates expressed concerns about the operation of the Office of the Public Guardian, and its interaction with other frameworks and safeguards:

"...when someone is under a public guardianship, advocates cannot often do their job as the public guardian does not regard advocacy goals as important, public guardian more interested in appeasing their own networks, PGs [public guardians] are not getting to know

³⁹ NSW Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

⁴⁰ NSW Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

the client, do not take on board their concerns, PGs have too many people to make decisions for and often do more damage to the client when decisions are not made well”

QLD Advocate⁴¹

“...do other advocates feel like they're doing the OPG's [Office of the Public Guardian's] job? ... Seems to be a lot a lot of things they should be doing and following up, that we are doing.”

“...Urgent decisions that need to be made within 24 hours, and we are still waiting weeks, we are doing the chasing up, because they are not doing it.”

“And then when it come to a head with vulnerability, where somebody is going to become homeless because the OPG hasn't done their job.”

QLD Advocates⁴²

[QLD Advocacy Organisation] “often experiences issues in trying to deal with OPG. OPG are often difficult to get a decision from as it appears they are drastically under-staffed and it takes weeks to get a response to an email. OPG have also obstructed ...advocates and refused to co-operate with our advocates in the past. ... OPG rarely develop a relationship with their clients and often make decisions without consulting them directly. This is largely a workload issue for the guardians. OPG should have sufficient staff to allow them instead to engage in as much supported decision making as possible to minimise the human rights impact of their guardianship power. At the moment, this is seen as too time consuming so OPG simply makes the decision that it thinks is best. This is often done in consultation with the family or service providers who have their own agendas that do not necessarily coincide with the best interests of the person with a disability.”

QLD Advocate⁴³

“NDIS QLD safeguard commission - OPG – EPA [Enduring Power of Attorney]. Commission have advised they will not pursue if OPG or EPA involved.”

QLD Advocate, December 2020 Zoom workshop with DRC

Advocates also expressed concerns about the operation of guardianship and administration frameworks across different jurisdictions:

“We think in WA there needs to be a look at the role of guardianship and administration in restrictive practices because we know that obviously people who have guardians often don't

⁴¹ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

⁴² QLD Advocates, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

⁴³ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

have all of those safeguards around them. They are in the segregated settings, they will experience restrictive practices. In some instances, guardianship acts as the restrictive practice and is used to restrict someone inappropriately.

So I think there needs to be a look at in general the relationship of the guardian system, guardianship system in WA to abuse, neglect and violence because, yeah, it is a best interests system, not, you know, a person's choice system and I think it's a key issue here for the state."

WA Advocate, October 2020 Zoom workshop with DRC

"The other thing that I would add is that it's not just the institutional advocates. Sometimes when the guardian is a family member, we've had issues with that guardian actually being more interested in controlling the behaviour of their family member and not understanding restrictive practices and behaviour support and if this has been going on for years, the family is happy to have them still medicated, still locked up. So we've had issues with other guardians, guardians generally, not just OPG and organisations like that."

QLD Advocate, December 2020 Zoom workshop with DRC

"...this very same group of advocates that you're talking to, we raised an unintended consequence when the NDIS came in because they ...didn't look at their legislation and then how it impacted on other legislation. So we said at the time as a group that we were really worried about the unintended consequences of people taking guardianship, families taking guardianship, where they wouldn't necessarily have had to do that and they took guardianship so that they could be nominees in the NDIS world and have a say in their son or daughter's plan where they wouldn't have ordinarily taken guardianship before and that's been a serious consequence I think and totally unnecessary.

So when you think of what can be done, well, before governments legislate, they need to look at other legislation that they have and see how it's going to impact, what the impact will be on people with disability because I think that was something that could have easily not happened in the first place and advocates said that there was an issue and no one really looked at it and therefore nothing was done. So here we are years down the track and we've got more and more people under guardianship unnecessarily."

TAS Advocate, November 2020 Zoom workshop with DRC

"...from my experience in working in a group home, you are talking about people, in some cases, people don't have necessarily the money skills. But, yes, the question of guardianship is quite fraught. I know one person who ... it was under a public guardian who then said, "Actually we haven't made a decision for this person in three years. We think that they no longer need public guardianship" and it required the intervention of their key worker in the

group home to say, "Actually, this person can't be making these decisions", but in that case, the public guardian just went, "Oh, well, we haven't made a decision for them; therefore, they don't need a public guardian" and that person had no family at all and I don't know where that person would have been left."

NSW Advocate, March 2021 Zoom workshop with DRC

Advocates also identified the limited nature of a framework concerned only with NDIS-funded supports alone, and the gaps in protecting people's rights:

"So I think the safeguarding area could actually be reviewed and even if you look at the NDIS now, well, if you were worried about a provider, you can report to the Quality and Safeguards, but what about if you're worried about a family member or what about if you're worried about a neighbour exploiting someone? You know, ... you can actually see a lot of worrying things happen across mainstream universal services but you can't... they're not all registered with the NDIS. So where are we going to go to safeguard people? What are the safeguards that exist? I don't think there are enough of them."

TAS Advocate, November 2020 Zoom workshop with DRC

The gaps in rights protection extend to the oversight and monitoring of restrictive practices:

"...we've had reports come to us from really concerned service providers about individuals living in family settings where restrictive practices are in place and they don't want to jeopardise their relationship with the family by intervening too strongly but are really concerned because the person clearly would benefit from more say in what's happening in their lives, and I think that's an area that we certainly have come across and would like to do some more work in. And I'm just wondering in terms of how do we address that, I guess regulations are always really tricky but it's about having that independent observation of the person's situation to ensure that their rights are being upheld."

SA Advocate, December 2020 Zoom workshop with DRC

"We've got a real problem in Tasmania with reports that go to the Senior Practitioner for assessment of restrictive practice. That's been a longstanding issue and in the last, well since the transfer to the NDIS, you couldn't report to the Senior Practitioner whether there was a child that had restrictive practices, but that's been changed recently sorry, before the transition to the NDIS, you couldn't report. It was only adults that you would report to the Senior Practitioner for assessment about restrictive practice.

Now children can be reported, but they have really low numbers of report. So even in the education system we would see exclusion, so any child that's been excluded in education, suspended, attending part time where there's behaviours of concern involved, there's nearly

always restrictive practice involved. So I can't give you an exact percentage but, you know, a lot of the advocacy cases that we deal with in education involve some kind of exclusion."

TAS Advocate, November 2020 Zoom workshop with DRC

For examples and commentary on issues in Victoria and other states see Section 12: [Failures of accountability](#) and [Restrictive practices](#).

Section 4: Features of quality services⁴⁴

In the course of the work they do, advocates generally become more familiar with the features of services that are of poor or low quality or are unsafe or harmful. Therefore, the commentary of advocates has been largely focused on service problems, including the lack of safety in accommodation and other contexts. See Section 12 for more descriptions of these features:

- [Inadequate cultural change and staff training](#) resulting in:
 - [Lack of choice and control](#)
 - [Reliance on restrictive practices to control "behaviour"](#)
- [Lack of human rights](#)
- [Profit-driven services](#)
- [Segregation and isolation](#)
- Problems with [Attitudes and culture](#)

In contrast, advocates described the need for quality services that:

- pay attention to the needs, will and preference of the individual with disability;
- support their autonomy, control and choice;
- uphold their human rights;
- recognise "behaviour" as communication and work to resolve problems, rather than resorting immediately to restrictive practices;
- are trauma-informed; and
- pay attention to addressing negative attitudes or culture and demonstrate leadership at every level of their organisation and in the related systems with which the individual with disability interacts.

⁴⁴ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p6. Question 2 asked: "How can quality services help to prevent violence, abuse, neglect and exploitation of people with disability? What are the features of those quality services?"

As argued by a number of submissions, including People with Disabilities WA, “taking a human rights approach to service delivery and providing safeguards for people with disability is the pathway to upholding their right to choice and control and protecting dignity of risk”.⁴⁵

Attention to the needs, will and preference of the individual with disability

Advocates shared many instances of neglect, sometimes due to a lack of training or resourcing and other times strongly driven by negative attitudes and culture within the organisation. See [Section 12: Examples – neglect](#) and [Attitudes and culture](#) below.

In contrast, quality services are those that pay attention to the needs, preference and will of the person with disability – providing opportunities for support workers to develop familiarity and share their learnings with relevant team members.

“I sometimes feel that the support workers don't really take the time to get to know their client. ...It's going to take awhile but really get to know your client because if you can't... if you really get to know your client you will see the triggers and you will know how to divert that before it gets to that stage, as opposed to putting in new staff who are undertrained with that client where... having new staff could inflame the situation. So to have that consistency in there with the same staff...”

QLD Advocate⁴⁶

“There is also a lack of clear communication between services and human service workers about the role of the human service worker in supporting the person with disability. What is most commonly conveyed is the day, time and length of the 'shift'. Services and system need to listen more to the person with disability.”

SA Advocate, April 2021 Solutions focused workshop with DRC

“I would just like to offer another perspective from someone who has worked in direct support... just about the people that I worked with who have had behaviours, or I like to think of it in terms of the people that I work with, the situations that they get anxious in, and that they are trying to communicate, which it sounds like we're all on the same page about that distinction... We noticed a really massive lack of communication between the service provider, the people who are employing the direct support workers, the Allied health and the family and then between the individual workers and the individual themselves. It's all this communication breakdown.

⁴⁵ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2021) *Overview of responses to Safeguards and Quality Issues paper*, p5.

⁴⁶ QLD Advocate, "Advocates Zoom In On... *Safeguarding rights and wellbeing*", December 2020 Zoom discussion

So we just started having, funded by the individual's NDIS plan, I guess not everybody has access to the same amount of funding. But in the instances when people did, we would have fortnightly meetings where everybody would come together. So everybody that works with that person, their family, any relevant allied health people, therapists. I'm thinking of this one person, who for many years has struggled to communicate a particular situation that they get very stressed out in. The approach had ... been to reduce the behaviour, and even through getting together and talking about 'I've noticed when this person is in a certain situation, this happens' and their voice is being really central to that discussion as well. We were able to flip the approach from reduce the behaviour to 'how do we facilitate this person's ability to communicate when they are not comfortable in a situation?' Since that approach has been taken on, the behaviour has been cut 80%. This person is now able to say 'I'd like to go' or 'I would like to leave'. ... getting everybody together on a semiregular basis is the key."

VIC Advocate⁴⁷

"We are self-managed. We have been for 10 years. I know that if my daughter was in a traditional service provider situation they would look to have her locked in and possibly have her medicated. She doesn't need it. We train her workers really, really well so that they get to know her and understand her. She is verbal, but she doesn't understand how to communicate her emotions and doesn't always react the best way and she's certainly not the most difficult person to work with at all, but I can see how she could be perceived that way and how this would build up over time and by the time she was in the hands of the service provider for a couple of years, oh my goodness, she would have a million dollar package, totally unnecessary."

QLD Parent⁴⁸

The increasing casualisation of staff also undermines the quality of care provided by support workers who have not had opportunity to establish familiarity with the preferences, needs and communication style of the person with disability, and document this knowledge for other team members.

"...the disability sector is largely casual. I have worked previously to my advocate role as a support worker. many service providers only offer casual employment. The pay rates are disgusting, we need to be paid as a reflection of our training. the government certificates in relation to disability and aged care are often pushed on the long term unemployed. Basically you get what you have paid for. the institution trained staff need to go or be retrained."

VIC Advocate⁴⁹

⁴⁷ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

⁴⁸ Advocate/Parent of child with disability in Zoom discussion, 2020

⁴⁹ DANA's 2020 Segregated settings survey, Response from VIC Advocate

“Red flag is often the high rate of staff turnover and the high use of casual ...staff coming in from outside agencies. High staff turnover often suggests issues within the group home and/or the broader service. There will always be a need for casual fill in staff.

Casual staff that are called to fill a shift in the context of frequent changes in staff - are often destabilising for residents in group homes as it is a change and both the casual staff member and the PWD [person with disability] do not know each other well.

I have found group home services that have a bank of regular casual staff they call in, have a far more positive focus and overall feel to the overall service and the group home itself.”

VIC Advocate⁵⁰

Autonomy, control and choice

In DANA’s 2014 engagement with disability advocates about progress on the National Disability Strategy 2010-2020, some survey respondents acknowledged an increasing understanding of person-centred approaches among disability service providers, yet noted that it remains highly inconsistent and dependent on individual workers. They also expressed apprehension that positive changes would not reach all intended beneficiaries, without additional measures for supporting access and for building capacity for self-directed supports, planning and self-advocacy among participants.

Some were also wary of signs indicating: *“reversion of thought within government and service sector that seeks to restrict and limit opportunities for people with a disability and their families by a risk management approach to change.”*⁵¹

There was also concern about service providers making changes that were only superficial - using language to mask failures to truly embrace self-direction or self-determination:

“Person centred planning is a buzz word that usually means we can meet your personal needs and wants but only within the confines of our congregated or segregated service - so maybe people get to choose what they wear from their cupboard of donated/second hand clothing, or maybe they get to choose to go dancing but only at the day option not the local pub.”

QLD Advocate⁵²

“Service providers have run community engagement programs without offering choice and bussed people with disabilities to a local club as an engagement, instead of asking the person

⁵⁰ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

⁵¹ DANA’s 2014 *Personal and Community Support* survey, QLD Advocate

⁵² DANA’s 2014 *Personal and Community Support* survey, QLD Advocate

with disability about their particular interests and seeing how that person could be welcomed into the local mainstream art society, or train watchers, or birding or golf, swim club or footy.”

NSW Advocate⁵³

The high-jacking of such approaches as "person-centred" supports and "choice and control" is usurped by the service sector and regurgitated as a rebranded program of "choices". Yes the language is more broadly used, but the practices employed are far from valid.

QLD Advocate⁵⁴

Fast forward to our engagements in 2020 when the NDIS had been fully rolled out around Australia, advocates continued to see a great need for improvement in disability services and supports living up to the principles underpinning the NDIS ideal of “choice and control”.⁵⁵

Advocates called for more training and understanding of decision making rights and how to support the rights, self-determination and decision making of people with disability.⁵⁶

“I would go down onto the ground and actually I believe that the treatment that disabled people receive is a reflection of society's culture as a whole... for me it needs to actually happen on the ground with empathy and compassion training ... and then we go back to ... supported decision making. I think that's also an imperative form of training that people need to have that... just to... to rise out of that: ‘Oh but I know what's best for you’, that paternal attitude that comes with a lot of care for people that aren't perceived as ... ‘having capacity’.”

ACT Advocate, October 2020 Zoom workshop with DRC

“...staff were trying to make the decisions for them. Not opening up and looking outside the box. Instead, they were just making decisions that this has always happened, because that person has been institutionalised since birth. Always been in a group home and they don't look outside of that. So those options were never provided either. Just the assumption that they will always be there - which is really sad. This particular client could potentially live more independent just with a housemate and a staff member coming in to assist with meals and cleaning. The potential is there but the fact that the service providers aren't allowing those people to live up to that potential and help facilitate that, is a really sad thing.”

QLD Advocate⁵⁷

⁵³DANA's 2014 *Personal and Community Support* survey, NSW Advocate

⁵⁴ DANA's 2014 *Personal and Community Support* survey, QLD Advocate

⁵⁵ See [Section 12: Lack of choice and control](#).

⁵⁶ See Section 5: [Supported Decision Making](#)

⁵⁷ QLD Advocate, "Advocates Zoom In On... *Safeguarding rights and wellbeing*", December 2020 Zoom discussion

“...you've got to balance duty of care versus dignity of risk and that's a very difficult thing to do, especially when you're dealing with guardians and administrators who would generally err on the side of caution when working with a client so that they'll generally try to keep the client safe and stable rather than acquiesce to their desires and wishes which they should within their rights be able to do.”

TAS Advocate, November 2020 Zoom workshop with DRC

“...one of the other things is that people hide behind duty of care and they forget that upholding people's human rights is an aspect of duty of care, but they totally just don't get that, so people's right to take a risk. But one of the really fundamental problems is that people with disability are seen as less than and those who need to be protected, as opposed to, you know, risk takers like the rest of us and have that opportunity for risk.

The Public Trustee ...It's just they hold people with disability to a completely different standard than the rest of us are held....So it's this fundamental issue around they're seen as 'less than, need to be protected'... and there's not enough focus certainly on rights.”

TAS Advocate, November 2020 Zoom workshop with DRC

Human rights training

Beyond training in supporting decision making, advocates highlighted the need for more general training in human rights and the rights of people with disability, including the right to make complaints and the rights to live free from abuse and with the least restriction of their autonomy:

“We've really got to start with educating people. Service providers and support workers. About, you know, what is a strict, restrictive practice and what is abuse? Because sometimes people think that what they're doing is normal and acceptable. So for example... thinking it's okay to give people dosages of drugs to sedate them because there's not enough staff to support them is a form of restraint and people might not think giving someone a sedative is restraint. So it's really fundamental that people have education and understanding about these issues so that they can differentiate and they can understand what is abusive behaviour and what is accepted or acceptable legal behaviour...So education and information on this is fundamental on all levels, and putting in place, systems of policies and processes that safeguard against this, this kind of behaviour happening is also pretty important I think.”

ACT Advocate, October 2020 Zoom workshop with DRC

“...looking at all of the staffing in group homes, probably across the board, really. I am not sure how well-trained staff in group homes are in relation to a rights-based approach. So that

would be a significant starting point, I think. Propping up even Cert two and three courses [Qualifications in Disability Care and Individual Support] with a rights-based underpinning to... that people have rights and they deserve to be treated in certain ways. If staff across a whole organisation carry that approach, then potentially it is a protecting factor.”

VIC Advocate⁵⁸

Recognition of ‘behaviour’ as communication

Advocates spoke at length about the over-reliance on restrictive practices they have observed in disability services and in other domains such as education. Restrictive practices can lead to trauma, isolation, escalation, and deterioration or under-development of the decision-making skills of the individual restricted. (See [Section 12 – Reliance on restrictive practices to control “behaviour”](#))

In response to an example of an advocate’s creative detective work to find and address the cause of a client’s “behaviour” through a care team and change management approach,⁵⁹ one advocate noted:

“...a big list of what’s not working does not tell us what does work. Case studies and learning, hearing the stories about what is working, and if they can be instituted, ideally the staff will be doing that and [an advocate] would not have to be the detective. That is what we need, we need the list of what to do...”

VIC Advocate⁶⁰

“Practitioners and services ... need to reconsider the idea of ‘least restrictive option’ with a means of balancing dignity of risk and the values of the person with risk to the person and the community. It seems that little work is done to determine how people with intellectual disability want to manage their own risks, and there is little work to determine how they view risk and danger. Many restrictive practices are based in part on community expectations and standards, rather than on what PWID [people with intellectual disability] actually want. There needs to be a mandatory consultation phase with the person themselves, if they are able and wish to participate. I have seen BSPs [behaviour support plans] written for people where the practitioner has not met the client and has based the restrictions around their best guess about what might work. This seems deeply unethical and problematic if we aim to make RPs [restrictive practices] more transparent and rights based.”

QLD Advocate⁶¹

⁵⁸ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

⁵⁹ See [Example – Creatively exploring causes of “behaviour”](#)

⁶⁰ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

⁶¹ DANA’s 2020 *Restrictive Practices* survey, Response from QLD Advocate

"I would say, though, that where people have very minimal restrictions because of certain compulsions of their disability, that where they are included in decision making and their capacities are scaffolded so that they take part in that and that they have an understanding almost to the point where they have been able to agree that in certain circumstances and at some points in time the most minimal restriction may be employed, then they're part of that process and therefore it's much more likely that those restrictive practices would be reduced immensely... reduced and eliminated and we know of a couple of people where that's happened. But that is not what usually happens for people."

QLD Advocate, December 2020 Zoom workshop with DRC

"...about employing behavioural support specialists. We've had some in participants' plans where having a proper behavioural support plan to prevent restrictive practices has worked really well with some of our clients, although they're very expensive, they're hard to get into plans, you know, to get a behavioural support plan is extraordinarily expensive. It's also hard to get one funded in someone's plan."

But we have had success with behavioural support specialists who will go in and train support staff if there's enough money and that has worked really well with some of our complex needs clients, but then again, you need to have a lot of money in your plan, but that has worked successfully for us. But yeah, it's only for clients that have a lot of funding in their plan, basically. But then other clients that don't have a lot of funding in their plan, there really is that gap with support staff having experience or training and all those kinds of things and the staff that don't often resort to restrictive practices. That's what we've found..."

VIC Advocate, February 2021 Zoom workshop with DRC

"...there being such a significant demand as well for disability support services that then in turn leads to quite a high number of either turnover of support workers or people being employed at such a fast rate that then they perhaps, for a whole range of compounding factors, aren't given maybe the appropriate kind of training or don't have that kind of understanding that reactive behaviours.... aren't always, I guess, person centred. So you might have staff who haven't been working with that individual for very long a time who then see quite high risk behaviours occurring and then immediately leap to restrictive practicesas a reaction, instead of, like, making informed decisions about how to manage that."

SA Advocate, December 2020 Zoom workshop with DRC

"I think for the people that we advocate for, they complain all the time about things not right in their life, formal complaints about things less readily, but people I think are very good at identifying what's not okay in their life. And again I think, as a number of people have said, it's actually about listening to people and listening to people means listening to 'behaviour'."

... I think services are not good, I think that lots and lots of people, the majority of people that are in the life of a person who's marginalised don't listen."

SA Advocate, December 2020 Zoom workshop with DRC

"...definitely training, more in looking at people holistically so that you're looking at people particularly like in the Education Department around sensory issues and addressing rather than reacting to behaviour, it's being proactive, like upskilling teachers. They haven't got enough training and particularly understanding ASD [Autism] I would say in particular, what we've come across. It's upskilling people and not just to tick it off to say well, they've got some training in this, but really putting in an effort to work on okay, the behaviour is the end result, so what's the need and coming at it from that perspective and working on that and trying to fulfil that part of it rather than just reacting and then right, you need a restrictive practice. So identify the needs, work as a team and address that and there will be a reduction in 'behaviour'."

SA Advocate, December 2020 Zoom workshop with DRC

"I think in some cases I've seen with positive behaviour support practitioners coming on board, a fresh set of eyes coming in to, say, a group home accommodation setting and seeking, you know, establishing alternative avenues so there isn't such a reliance on restrictive practices where there are perceived dangers, I suppose, or risks. So some positives there, but then still numerous situations where it's clear that what's needed is more allied health professional involvement, but having difficulty securing funds or whatever it may be."

VIC Advocate, February 2021 Zoom workshop with DRC

"I used to be a planner but things have changed. We didn't have LACs [Local Area Coordinators] when I was a planner, but I'm finding from an advocacy point of view I need more and more evidence to argue for a behavioural support plan initially and I suppose the whole idea is a behavioural support plan builds capacity and then theoretically they hope that the need for behavioural support funding will reduce and I think they still just pull it in initially for six months the amount of funding to build the capacity. But I'm finding I really have to provide a lot more evidence and reports to get that funding."

WA Advocate, November 2020 Zoom workshop with DRC

(See Section 12 for further discussion of [inadequate staff training](#) and [Profit-driven services](#).)

Trauma-informed organisations

Quality services are trauma-informed:

“... it needs to actually happen on the ground with empathy and compassion training... We've lived it. People [with] lived experience being able to tell their stories and have experiential training so that support workers actually get the opportunity, as limited as it would be, to feel and experience trauma or situational experiences... scenarios... Trauma-informed care in practice should be mandatory for anyone dealing with someone with disability. And I say that because the majority of people with disability, as we know the disgusting statistics of women with disability suffering sexual abuse and assault. So for anyone dealing with people with disability, I believe that it should be mandatory trauma-informed care so that they're understanding how trauma affects the brain and therefore how it affects behaviours and what type, then, of support a person with disability needs and wants... the current training does not do trauma informed care and that's something that organisations may provide once they have started employment. So I just think yes, the training needs to be completely overhauled because it's not satisfactory.”

ACT Advocate, October 2020 Zoom workshop with DRC

Trauma-informed organisations recognise that the use of restrictive practices can often result in trauma:

“... fundamentally a lot of the time it causes trauma and then a lot more issues down the track. So like we had ... like a particular client who was ... locked up and ... is now living alone, but she's having a lot of ... there's a lot of behavioural manifestations of that trauma which is making it really difficult, which is distinct to her disability, but which occurred because of the abuse that she obviously experienced as a result of her disability. So I think that's kind of the most fundamental aspect I think I've seen, just the trauma that it ... brings about.”

ACT Advocate, October 2020 Zoom workshop with DRC

During the course of the Royal Commission, short films about trauma informed support have been produced through the National Disability Services Zero Tolerance initiative,⁶² and guidelines have been developed to guide trauma-informed practice for those supporting people with disability, funded by the Department of Social Services.⁶³ However, overall, there has been limited awareness, training or development across the disability sector in how to ensure organisations and services are trauma-informed (including by actively working to prevent further abuse and trauma).

⁶² National Disability Services (2020) [Trauma Informed Support Films: Facilitators Guide](#). See the [short animations on vimeo](#).

⁶³ Dr Cathy Kezelman and Julie Dombrowski (2021) [Disability Guidelines for Trauma-Informed Practice: Supporting people with disability who have experienced complex trauma](#), Blue Knot Foundation – National Centre for Excellence for Complex Trauma, Australia. (There is also a [plain English version](#).)

Organisational and sector leadership to ensure cultural change

Advocates spoke extensively about “culture” and attitudes that permeate disability services and other services systems – this includes negative and outdated attitudes about disability and cultures that ignore, downplay or even enable violence, abuse, neglect or exploitation of people with disability.⁶⁴

One theme that emerged during discussions was that leadership within disability services is needed to ensure cultural change is occurring at every level and throughout every part of the organisation. There also needs to be sector-wide leadership and cultural change across all systems that people with disability interact with, to ensure the rights of all consumers are upheld:

“...sometimes there is an attitude that comes from the head down and sometimes it's just the amount that they invest in their staff in terms of education and training. So I'll just use an example I've just come from a discussion recently with [... a] LGBTI group down the hall from us, and they say that groups that employ them to do education around safe practices for LGBTI people find that they have a lot less attitude problems with their staff who they know what the rules are, they know what's okay to do and we see that in other ways as well, so where attitudes are encouraged by an organisation, positive attitudes towards people, appropriate behaviour, appropriate use of restrictive practices, then people who work for those organisations know what's expected of them and they know what's okay and what they can't get away with.”

WA Advocate, October 2020 Zoom workshop with DRC

“It's so variable because we [work with clients] in a number of group homes and one institution. I've noticed that... over many years, it seems to come from the top. If a service is good, it's not a guarantee but if they have the right kind of... It's nothing to do with what is written in the policy manual because sometimes the services who have the best, actually have the worst practice. If there seems to be a culture of respect and not looking for restrictive practice, I'm just waiting for that one because I have someone, it's such a current issue. What I noticed is that the better service, if management is responsive, then if someone isn't so fantastic, they will find a way of moving them on maybe to somewhere else, which is not ideal but I think it is so variable. Maybe it's getting better? I don't know. It's impossible to say. I find that in a group home, for example, or even a unit within the institution, if the people at the top seem to be better, that particular place can be better. It's just about the culture and the organisation, specifically in group homes.”

NSW Advocate⁶⁵

⁶⁴ (See Section 12: [Attitudes and culture](#))

⁶⁵ NSW Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

“Before I was in my role, I was doing direct support and we don't do group home staff at the organisation that I worked for but there was a day centre there and what I noticed to be really successful was an initiative that the managers put in place which was like a peer learning situation where we would have a monthly meeting or get together, everyone who works in a program, and discuss what was working really well, challenges that might be coming up, and during that process, which was facilitated by somebody who didn't work for the organisation as well - I found that really useful. ... about the culture and it being really baked in. I see it as twofold. The cultural aspect and then the training. Both things are really important. I can say that from the perspective of someone who has been in that support role.”

VIC Advocate⁶⁶

“I think training and education of supports and people who are around people with disability is important, but I feel like if the focus is too much on education and guidelines and rules, regulations, it all becomes a bit of a tick a box exercise. It needs to be a cultural change because again most of the people... essentially people will join an organisation, they'll get taught this is the way we do things and then do it that way regardless... If you focus too much on the training, we focus too much on these other guidelines you have to adhere to, we'll miss the true goal which is actually supporting people as best we can.”

SA Advocate, December 2020 Zoom workshop with DRC

“Any organisational change needs... strong vision, leadership, policy and procedures, legislation, independent auditing, independent advocacy,”

NSW Advocate, March 2021 Zoom workshop with DRC

“My concern is, I believe that training is essential to get improvements but my fear is that whoever heads up any of these organisations has to have a philosophy about disability that's not one that I have seen a lot of, which is there's not essentially... can we get these people better. It is about their inherent, independent role in society and how they are valued members of society and how society needs to treat them as valued members of society.

I fear that without that headstrong approach and philosophy from the heads of all government departments, anything that we suggest will not get very far because from what I can see from my role, if the head of a department is very, very on board with that philosophy, whether or not your staff are well trained, they will be well trained. It will get done, but if they don't have

⁶⁶ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

that philosophy and they have a self-interested philosophy and the philosophy of ...somewhat charitable philosophy about disability, it doesn't get done."

NSW Advocate, March 2021 Zoom workshop with DRC

"Provider education is very important but there needs to be a strong commitment to people with disability at every level of the organisation. There should be representatives of the cohort on Management Committees and Boards as well as in leadership positions in the operational side of organisations. Just doing training once a year is not enough, staff turnover can be a big issue."

NT Advocate, April 2021 Solutions focused workshop with DRC

Access to independent advocacy and support to make complaints

Advocates expressed fear that the barriers to making complaints and ineffective oversight mechanisms mean that many people with disability in need of independent advocacy are effectively blocked from accessing an advocate:

"As an advocate I have been to guardianship hearings to support clients but not ever contacted by a service regarding restrictive practices."

"I have had some providers make referrals to advocacy, but other providers are clearly wary of advocacy services."

NSW Advocate, March 2021 Zoom workshop with DRC

"...we don't know what we don't know and the case that we're looking at, the use of chemical restraints and the over-prescription of medication used incorrectly in some of the group homes, they're certainly not going to be seeking an advocate for the resident. So I just think we don't ... I think the problem is probably worse than we think in a lot of senses because again, as everyone said, the NDIS Commission is a toothless tiger, so people don't even bother going to report to them. So where do you go? I think that's a real issue that we don't know, we can only speculate how big the problem is because the person themselves is not in a position to seek out advocacy."

VIC Advocate, February 2021 Zoom workshop with DRC

Section 73W of the *National Disability Insurance Scheme Act 2013* requires "registered NDIS providers to implement and maintain a complaints management and resolution system that":

(aa) acknowledges the role of advocates (including independent advocates) and other representatives of persons with disability; and

(ab) provides for cooperation with, and facilitates arrangements for, advocates (including independent advocates) and other representatives of persons with disability who are affected by the complaints process and who wish to be independently supported in that process by an advocate or other representative...”

In theory, providers have an obligation to allow a person with disability to receive support from advocates during a complaints process.⁶⁷

However, as described above in [Section 2](#), people with disability may:

- experience fear or hesitation to voice complaints;
- lack awareness of their rights to complain;
- lack trust or confidence in complaints mechanisms; and/or
- be segregated or isolated without support to speak up;

In practice, advocates have observed providers who engage in ‘gatekeeping’ and little indication that there is meaningful access to advocacy facilitated by many providers.⁶⁸

DANA believes that disability services should be required not only to arrange access to independent advocates once a person with disability has made a complaint, but to also ensure that independent advocacy is accessible for people with disability who may need support to voice their complaint (or to report abuse or mistreatment) in the first place.

Section 5: Developing capacity & strengthening informal safeguards⁶⁹

Advocates raised a range of ideas about strengthening informal safeguards.

To build more opportunities to create informal trusting relationships, Leadership Plus asserts that:

“NDIA Planning needs to provide additional and easily accessible funding for transport and support workers, to get people out of home and into society.”

⁶⁷ See also [NDIS practice standards | NDIS Quality and Safeguards Commission \(ndiscommission.gov.au\)](#)

These standards include three indicators that mention the right to access advocates under the outcome headings of ‘Independence and informed choice’, ‘Violence, Abuse, Neglect, Exploitation and Discrimination’, and ‘Feedback and Complaints Management’, including some mention of providing information about that right.

⁶⁸ See more discussion of this topic in Section 8: [Ensuring access to independent advocacy for people with disability at risk](#) below.

⁶⁹ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p6. Question 8 asked: “How can informal safeguards be strengthened to prevent or reduce violence, abuse, neglect and exploitation of people with disability? What are the ways in which people with disability develop personal capacity to safeguard at different stages of their lives and as circumstances change? Are there systems in place to support this capacity development?”

Their submission explains that exploring mainstream community groups provides NDIS participants with opportunities to create new informal connections and build stronger safeguards.⁷⁰

In relation to developing the personal capacity of people with disability including their capacity to safeguard at different stages of their lives, and as circumstances change, independent advocacy organisations could potentially play a much stronger role, if adequately resourced.

The role of independent advocacy organisations

As discussed in Section 1, access to independent advocacy, and the developmental work that advocates and advocacy organisations do to protect rights and build rights awareness, function as safeguards that respond to and prevent violence, abuse, neglect and exploitation. Independent advocacy develops the capacity of people with disability to protect and speak up for themselves:

“Many don’t recognise what’s happening is restrictive and taking their rights away. So having the power to speak up about something when you don’t recognise what’s happening is impossible, you know, without someone independent there letting people know.”

TAS Advocate, November 2020 Zoom workshop with DRC

“Some [people with disability] are certainly extremely vulnerable and often targets of would-be predators and those seeking weakness to take advantage of in whatever way they can. Independent advocacy, that is advocacy that is in no way attached to services provided to people with disabilities, is one of the most powerful safeguards available. Being free of conflict of interest, independent advocacy can, as it should, focus on the needs of the vulnerable person/people. It can also seek out people who are vulnerable and would otherwise not access any advocacy or complaints mechanisms. We know that the very presence of advocates in the lives of vulnerable people makes a difference to how service staff respond. They often become more diligent and careful about meeting the person’s needs. In some forms of independent advocacy, the advocates become familiar with the vulnerable person to the extent that they can respond with relevance and potency to issues as they arise and even help avert crises. Independent advocacy can improve the positive impact of services by ensuring that services are targeting the real needs of people (being relevant) and reducing the over servicing of people also (ensuring a developmental focus as the person grows in knowledge and competency).”

SA Advocate⁷¹

⁷⁰ Leadership Plus (2021) *Unsafe at any speed – A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability: Re: Safeguards and Quality*, p6.

⁷¹ DANA's 2015 Quality and Safeguards survey - Response from SA Advocate

“Advocates provide valuable insight for systemic reform to governments, services, and community about harmful practices, ill treatment and violations of human rights. Advocates also instigate and educate family members, community, services and government about alternative ways to support people with right relationships, supported decision-making and best practice.”

QLD Advocate⁷²

“...a message that needs to go clearly to the DRC and that's about helping to address to some small extent the significant and innate power imbalance that invariably exists when you've got a vulnerable person dealing with an organisation or a system and giving a voice to someone who's not going to otherwise have a voice. And I think that's really powerful, not only actually in being able to practically assist and in providing the support and capacity building and empowerment for the person, but sadly there actually often is a difference in response that you get from the organisation or service provider when an advocate is involved - when there is transparency, when there is support for the person.”

QLD Advocate, April 2021 Solutions focused workshop with DRC

“From our perspective, advocacy can be the observer witnessing the behaviour and the practice of service workers and uncovering things from alongside the marginalised person. Others generally, when they go into a setting, they observe the person rather than observing what's happening around them, and so we get a whole lot of environmental stuff that impacts on what's happening for a person, particularly around when people use ‘protest behaviours’. And we see that a lot, protest behaviours are just a form of communication, and so when we're observing what's going on around, for instance, a fellow who didn't want to go swimming who loved swimming, and the reason he didn't want to go swimming was because of the support worker that was taking him. Advocacy could observe that because they'd observed that swimming stuff happening many times and this was what was different.

I also think that... we would talk about that advocacy relates to the person and listens to their ... wants and needs separate from service constraints. So we don't have to think about programatic stuff, we're just listening to what people want and helping to influence the decisions that are made about that. Advocacy has no skin in the game, for want of a better word, in regards to being served by the outcome, so that's the independence. When advocacy is watching, services are more likely to treat the person well. There's an inherent cookie cutter kind of response to the needs of people with disability within service and government systems, and advocacy challenges them to do better. Advocacy is a human response, I think, to the lived experience of people with disability, and advocacy will act.”

SA Advocate, April 2021 Solutions focused workshop with DRC

⁷² DANA's 2020 *Advocacy and Abuse Prevention* survey, Response from QLD Advocate

“Advocates can role model respectful treatment and provide an experience of empowerment when working with people with disability. The person themselves, therefore, have an experience of what it’s like to be listened to, and supports around them witness this.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

In 2011, the Productivity Commission recognised the important role that independent advocacy would continue to play in the NDIS.⁷³ Advocates play a crucial role in protecting the rights of individuals, and also contribute to systemic improvement of the scheme. In addition, independent advocacy remains instrumental in addressing the inequities and injustices experienced by people with disabilities in other service systems and domains, for instance education, health, justice and housing, thereby optimising the intended ripple effects of the NDIS in the lives of people with disabilities.

A strong disability advocacy sector can serve as an additional external mechanism for preserving accountability and integrity:

“Independent advocacy is integral to support people with disability and their families - especially those most 'vulnerable' through the transition to NDIS and beyond. Without it, the NDIS will fail to realise its goals.”

VIC Advocate⁷⁴

“Independent individual advocacy has a focus on serious, urgent and complex need. It is resource limited and in demand.”

WA Disability support worker⁷⁵

Advocates also play a role in providing or connecting people with relevant information and resources:

“I’ve literally just had a client meeting this morning with a lady, talking about her husband in the home, and what is going on for him. It’s not so much abuse or violence, but potentially exploitation, and there are no supports in the home, and different things. I have just today provided some brief education and potential resources and referrals, and that sort of thing. This woman was like, “I didn’t know that existed.”

As much as I have said ‘I’m here to support you with your matter, but you have just mentioned your husband who you are meant to be caring for, and what’s going on there... did you know,

⁷³ Productivity Commission (2011) *Disability Care and Support Inquiry* report, Volume 1, p507-8

⁷⁴ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

⁷⁵ DANA's 2015 *Quality and Safeguards* survey - Response from WA Disability support worker

and can I send you those resources? And who else can I talk to, to provide that information within your informal supports?' And she has someone younger, and she said it would be great if you can explain it to her and she can explain it to me. I think our role is certainly education or referral, definitely."

NSW Advocate⁷⁶

"One of the biggest things is the independence that the advocate has to talk to people about their rights and what the options and choices are. Often in our role we might have family members saying 'this has happened', but they don't want to go to the police, they don't really understand what has happened. And I think the role of advocacy, to be really independent and make sure that everyone knows all of their options, is important."

TAS Advocate⁷⁷

"In our area, we tend to go speak about advocacy, a person's rights, abuse and neglect, what it looks like. This has been helpful in prevention of abuse and brought about disclosures. It is a time constraint, although it is helpful to do as prevention. This is done in our local groups"

VIC Advocate⁷⁸

"I guess the role is somewhat multifaceted, in terms of responding. Sometimes... it's about a service ringing to say, 'This has been reported, what do we do?' So we are guiding this service. If there's been allegations of physical assault, sexual assault, financial exploitation, it's about guiding that person who first reports, to support that person to go to police, and what needs to be put in place in terms of their end, with police; that there needs to be an independent third person with the person with the disability during the interview stage.

We also often act, particularly for people with disability that we know very well, we will act in terms of helping police and other authorities understand that person's disability, their behaviours, their communication style, educate around the disability itself. So, what autism may look like, what an intellectual disability [may look like], and how that presents in that individual.

We have a large role in supported decision-making. And that's a vital role for the person with a disability to be able to make a choice as to what they want to do. Especially around those things such as sexual assault. We all know that not every sexual assault is prosecuted. So,

⁷⁶ NSW Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

⁷⁷ TAS Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

⁷⁸ VIC Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

it's about that person having independent support to make that decision about what they want to do.

Sometimes it's not just a service, but family that are perpetrating abuse and exploiting [the person with a disability]. So, it is about how to safely support that person as to what they want to do. And we make referrals and link with vital services. So, if there is sexual assault, we will link with the sexual assault counselling service. We link with any other services that need to come in, whether that's... if someone has an administrator, we might have to get administration involved.

It's very much a coordinated, cohesive approach. And making sure that supports are in place for that person with a disability, so they are safe and feeling safe. If something has happened within a group home, for example, or SDA, the Specialist Disability Accommodation setting, is this individual feeling safe, and safe? What are you going to do? It is quite a multifaceted role and it's important.”

VIC Advocate⁷⁹

“Sometimes when matters come to court, legal practitioners need education about how to support a person at court. We'll come in and be an extra person at court, that is something else we do.”

VIC Advocate⁸⁰

“...advocacy is critical. Because the Government keeps creating intensely complex systems that are supposed to support people, people cannot access those systems when they don't have English as a first language. Without advocacy, you know, many of our clients and families would never be able to access the support that they need.

It's just , I can't even... I find it so frustrating that the Australian Government keeps creating intensely complex systems. The NDIS is impossible. It is just impossible for people to understand. They don't understand it. They don't go on the bloody NDIS portal, they don't know what the NDIS is or what it means or what it could be for them because it's just the whole system is being made stupidly and ridiculously impossible for people who don't have English as a first language, people who don't have computer literacy or access to the internet. Yeah, why, why did we make it so hard?

And you know what? The Commonwealth keep us advocates in jobs because of the idiocy of the way that we set up systems; because of all the barriers that we put in place to prevent people getting access to the services and supports they need; because the burden of proof

⁷⁹ VIC Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

⁸⁰ VIC Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

that is put on people if they need to access a Commonwealth service, we need advocacy. We need to be out there supporting people to get access to what they have a right to access, to get those basic supports they need to have a good life in their community. ...it's keeping bureaucrats in jobs. But because we set up systems like that, because you've got to prove all the time how much you need a service, advocates are critical."

NT Advocate, November 2020 Zoom workshop with DRC

"...as advocates with people that we know that live on their own, advocacy is a part of that kind of check-in and making sure that people are okay. [At our organisation] we advocate for people over the long term and we get to know them very well, but we also... a lot of our work is to try to help people to be embedded in their local community because when you are missed, then people are more likely to ask questions.

...So we would always encourage that people are a part of their local community, you know, they shop in the same place, they become known to people. And we see lots of people, we certainly do, who do live in their local community. They have gone to their local schools, they go shopping, whether that's on their own, whether that's with a support person, they are a part of their community. They haven't been bussed out of their community as kids go to special school; they haven't been, some have certainly, on that parallel universe where [there is] special school, special housing, special work.

These are the kinds of tracks that people get on and so ordinary community members just assume that the person is okay or they just assume that they don't need to be involved, whereas somebody who's living in their local community, and we do see this all the time, "Where's Jack? We haven't seen him for a while, is he okay?" ...these are the things that keep people safer by being known and not just known to people who are paid to be in your life, but known in ordinary ways."

SA Advocate, December 2020 Zoom workshop with DRC

"...lots of behaviours of concern or communication [are] because people feel powerless and you give them an advocate and you go through a process of helping them to determine what it is they actually want, you know, and a lot of the time you get to a place where it's just that that person actually wants something that the provider, or whoever, is saying that they can't have."

TAS Advocate, November 2020 Zoom workshop with DRC

For more examples of how advocates engage in developmental, preventative and corrective safeguarding measures in the course of their work, see Appendix C: [Advocacy and Safeguarding](#).

The different models of independent advocacy can contribute in particular ways to developing capacity and strengthening informal safeguards.⁸¹

Individual Advocacy

The model of “individual advocacy” is a one-on-one approach, undertaken by a professional advocate to prevent or address instances of unfair treatment or abuse. This may include:

- providing information to people with disability about their human rights and identifying instances of discrimination;
- assisting people with disability to uphold their rights by speaking with and writing to people and organisations to raise awareness of problems and seek solutions; and
- helping people with disability negotiate complaints processes or legal action to enforce their human rights.⁸²

Although individual advocacy tends to be more focused on achieving outcomes for the individual and less focused on developing personal capacity, advocates observed that it does build the capacity of individuals with disability to understand their rights, navigate systems, build trusting relationships and ‘find a way forward’.⁸³

“...if a person has had an experience with an advocate, they're more inclined to understand their own rights and be empowered. And there's that word, to Self Advocate. And that's the purpose of having a disability advocate... is to build capacity and someone to understand ... that they have rights. They are entitled to be treated as all citizens are treated, equally, equitably. I'm not saying that that actually happens on the ground and in real life, but yes, with an advocate by their side - if they've had that, they will be more...they will have more capacity to understand their rights and self advocate.

ACT Advocate, October 2020 Zoom workshop with DRC

“... I've supported a lot of people with the treatment orders. And a lot of it is actually attending SACAT [South Australian Civil and Administrative Tribunal] hearings and then helping them to understand the restrictive practice so they then understand why it's been in place, and trying to link them in to suitable services often outside of community mental health, so that they can get their own individualised access to people that they can build a trusting relationship with outside of community health sometimes, community mental health, so that

⁸¹ For information about each different model of advocacy, please visit this page of the [DANA website](#).for brief description and explanation videos about each of these models of disability advocacy, or access the National Disability Advocacy Program Operational Guidelines on the [Department of Social Services website](#).

⁸² See Disability Advocacy Resource Unit (2012) [What is disability advocacy?](#)

⁸³ Arguably, all advocacy organisations helping individuals engage in a “supporting self advocacy” approach - to some degree, supporting people to develop self advocacy skills and build capacity, whether or not they deliver specific self advocacy training or programs.

they don't ... it feels less forced and that they have more choice. That's what I find I do a lot of work around. I don't know how the other advocacy agencies work, but that's what I tend to do. So they have a voice, their own voice as well."

SA Advocate, December 2020 Zoom workshop with DRC

"I think it builds capacity for people, especially parents, to help access the NDIS for internal reviews or to tell their story with the Disability Royal Commission. People are sometimes at their lowest ebb and they don't know where to go and it's helping them build their own capacity and showing them a way forward and helping them submit applications, whatever that application may be. And sometimes we're seeing mothers at their wit's end that also are suffering from anxiety and depression themselves."

WA Advocate, November 2020 Zoom workshop with DRC

Citizen Advocacy

The model of Citizen Advocacy seeks to support people with a disability (also called protégés) by matching them with volunteers. Some of the matches made may last for life.

Through Citizen Advocacy:

- people with disability who are isolated with no family or community supports or networks are sought out;
- volunteers are encouraged to represent the interests of a person with a disability as if they were their own and be free from conflict of interest;
- volunteers are recruited, trained and supported by a coordinator who manages the work of the Citizen Advocacy agency.⁸⁴

Strong relationships and community connections reduce a person's vulnerability to abuse and provide support and guidance to remedy abuse when it occurs.

"...a citizen advocate is matched with a person with a disability for the long term, so [the citizen advocates] become part of their life, know the issues in that person's life and can help them deal with problems while they are still small and manageable."

WA Advocate⁸⁵

"The format is less about someone being a formal support for the person with a disability, and more about them being more like a peer ... That is a good model to me, taking away the

⁸⁴ See further information on Citizen Advocacy Trust of Australia website: [What is Citizen Advocacy? - Citizen Advocacy Trust of Australia](#)

⁸⁵ DANA's 2015 *Quality and Safeguards* survey - Response from WA Advocate

potential power imbalance that comes from... that is inherent in nature of a service provider and a participant, for example.”

VIC Advocate⁸⁶

“...the benefit of having a citizen advocate is [having] an independent person, and the people in our program who are part of a day program, more often than not, the citizen advocate will get involved with the day program to just find out exactly what goes on there and how they're faring there and if that is a good place and, importantly, if that's their choice to go there. Because we've had a couple of situations where the person in the group home has no informal supports, just been told day service, and with the citizen advocates involvement they've found that's not what they want to do. So, yeah, then that's given that person some choice and control over their life not to go to a day service.”

VIC Advocate, February 2021 Zoom workshop with DRC

For further discussion of Citizen Advocacy, see Section 10: [People who need additional support](#).

Self Advocacy

The model of self advocacy supports people with disability to advocate on their own behalf, to the extent possible, or on a one-to-one or group basis. Self advocacy training allows people with disability to gain and practice skills to help them voice complaints and have their say, to recognise when their human rights are being violated, and to report violence, abuse, neglect or exploitation that occurs. Traditionally many organisations have specialised in supporting and amplifying the self advocacy of people with intellectual disability.

VALID CEO Kevin Stone emphasised the potential of self advocacy at the Living in Group Homes hearing in December 2019:

“The only strategy I've ever seen capable of making a difference is advocacy and self advocacy, particularly self advocacy, empowering people to stick up for themselves.”⁸⁷

VALID Advocacy Manager Sarah Forbes outlined their approach:

“... there's a lot of work that VALID does in supporting self-advocates because our view is that the stronger self-advocates are, both individually and acting together, the more likely they are to get what they want and what they need. And so as – in everything we do, we use

⁸⁶ VIC Advocate, "Advocates Zoom In On... Advocacy for people from culturally and linguistically diverse communities", November 2020 Zoom discussion

⁸⁷ Hearing on Living in Group Homes - Transcript of proceedings - Day 3, Thursday 5 December 2019, Melbourne.

*an empowering advocacy model that seeks to raise people's voices to say exactly what they want..."*⁸⁸

AMIDA [Action for More Independence & Dignity in Accommodation] Projects Co-ordinator Pauline Williams explained:

*"So the self advocacy movement – and it's a civil rights movement, really, that grew up at the time that people were fighting to have institutions closed, and self-advocacy groups around Victoria and Australia are, you know, very poorly funded, I would have to say – but people have fought over the years to come together because they know that their voices are stronger when they come together, ... it provides that sense of, "I'm not alone and I can maybe do something about this and get some support." And we – we think that it plays a big role in sort of safeguarding people's rights if they're – if they're strong self advocates who stand up, they're less likely to have their rights infringed. And it would be really great if that model could be rolled out across Australia. I think it's been very successful in Victoria."*⁸⁹

Building personal capacity to self advocate goes beyond strengthening individual safety. One Victorian advocate explained the potential roles that trained self advocates can play in oversight and protection of other people with disability:

"...about accessing closed environments because the people who need to be accessing those environments, Advocates, are important, but self advocates are even more important. They see the things we don't see and know what they mean. They see the micro aggressions, they see the closed door. They understand the context in a way that somebody who has never lived or worked or spent significant time in such a setting doesn't understand it. We need to be breaking down the barriers between who is a trusted person and who is some charitable object of a service provider, and see people with disabilities as having useful and valuable experience that they should be able to be paid, to provide to others, and to get out in the community and do that..."

VIC Advocate, February 2021 Zoom workshop with DRC

One Tasmanian advocate also highlighted the preventative role that self advocacy training can play in influencing the quality of supports provided to people who are "connected to advocacy":

"...the preventive, so it's been really strongly evident... we co-facilitate self advocacy meetings monthly around Tasmania with members, and support workers say to us that just

⁸⁸ Hearing on Living in Group Homes - Transcript of proceedings - Day 4, Thursday 5 December 2019, Melbourne.

⁸⁹ Hearing on Living in Group Homes - Transcript of proceedings - Day 4, Thursday 5 December 2019, Melbourne.

the fact that they have.. that... clients have or members have an invitation to attend a Self Advocacy meeting with [our organisation] on a monthly basis is a prevention and they say this person in a four-bedroom group home who attends gets better treatment, because the staff are aware that they're connected to us, than the other three people in the group home.

So that's a really absolute stark example of the value of when they know people are connected to advocacy, that they're actually... they're a bit more aware and a bit more conscious and it's unfortunate for the other three people in the home, but it's fairly strong evidence that it actually works and it is a prevention.”

TAS Advocate, April 2021 Solutions focused workshop with DRC

A number of incredible self advocates have spoken powerfully of their experiences in DRC hearings so far, including some who have been employed part time at Council for Intellectual Disability (CID) or other advocacy organisations in capacity building projects for people with disability. (Self advocacy groups can be a particularly effective form of “peer support” – see discussion below in the [Peer support](#) sub-section.)

In recent years, many of these projects are funded through the NDIS Information, Linkages and Capacity Building (ILC) funding stream. This funding is largely project-specific and short term. In relation to the recurrent core funding, self advocacy has limited resourcing, as DANA CEO Mary Mallett told the Senate Community Affairs References Committee in 2015:

“Time and time again, what the advocates are telling us and what they see is that people do not complain—for many reasons. In the first place, they do not know their rights. They do not know they have a right to complain, and one of the few groups who educate people with disability about what their rights are, is advocacy organisations... That really important arm of advocacy, which is Self Advocacy by and for people with disability themselves, almost does not exist. It is done off the side of the desk mainly. Advocacy in general is badly funded; Self Advocacy has nothing really.”⁹⁰

“It happens relatively well in Victoria because the Victorian government fund a small Self Advocacy resource unit. It is the only one in the country and it makes a big difference in Victoria. It is one of the reasons Self Advocacy exists much stronger there than anywhere else and almost not in the rest of the country.”⁹¹

Dedicated funding to deliver Self Advocacy training and establish Self Advocacy groups is needed to teach people with disability about human rights, speaking up and advocacy. Advocacy organisations should also receive secure ongoing funding to maintain active Self

⁹⁰ Mary Mallett quoted by Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, Final Report p197.

⁹¹ Ibid, p 198.

Advocacy groups and networks, so that Self Advocates can attend regular meetings to share knowledge about rights and support each other to protect these rights.

Family Advocacy

Through the model of “family advocacy”:

- family members are provided with advice and support;
- the person with disability is assisted via the family members being directly supported by the agency to advocate on their behalf.⁹²

“Family advocacy” organisations work with parents and family members to enable them to act as advocates with and on behalf of a family member with disability. Family advocates work with parents and family members on either a short-term or an issue-specific basis. Family advocates work within the fundamental principle that the rights and interests of the person with disability are upheld at all times.

Parents and relatives naturally adopt the role of advocating for the human rights of their family member with a disability:

“...families can be important advocates for people with disability and when equipped with the right skills, they can be a ‘phenomenal force’.”⁹³

There are a small number organisations in Australia specifically dedicated to supporting and resourcing family advocacy, however other advocacy organisations also inform and support families in their advocacy efforts:

“[NSW Advocacy organisation] provided us with information and resources that enabled us to create a vision for [John] and to be in a position to maintain that vision and follow that through.”⁹⁴

“...we see time and again that family is imperative to the raising of awareness when it comes to abuse and neglect and holding that accountability - and so having the ability to build the capacity of the family through advocacy and actually acknowledging the importance of family as advocates is really imperative, one for the whistleblowing and naming, but also for when you're looking at the other side of the coin and making good things happen in a person's life, ultimately it usually comes down to the family. If they have better advocacy in talking with a school, for example, that leads to better outcomes for the student with a disability, and that student is seen as having a valued role as a student, and then they're treated in a different

⁹² *Models of Disability Advocacy*, Department of Social Services Website. Quote from NSW Family Member.

⁹³ VALID CEO Kevin Stone, quoted in the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability - Interim Report (October 2020) p378.

⁹⁴ Testimonial for family advocacy organisation

way by the teacher, and when they're treated more favourably by the teacher, they're treated more favourably by the child.

And this is the thing that flows on from one setting to the next when they then move on to their next phase of life, how they view themselves, how they are treated, et cetera, et cetera. So advocacy is absolutely vital, but also recognising that nuance... that the family's advocacy... needs to be recognised as well."

NSW Advocate, April 2021 Solutions focused workshop with DRC

Informal advocacy undertaken by families is both cost effective and provides an ongoing safeguard for the person with disability.⁹⁵

Legal Advocacy

Legal advocacy seeks to uphold the rights and interests of people with all types of disabilities by addressing legal aspects of instances of discrimination, abuse and neglect.

Types of legal advocacy include:

- legal advice and/or representation from a legal professional;
- community legal education programs and information services; and
- non-legal support, including but not limited to organising referrals, facilitating meetings, navigating processes, interpreting or translating information.

As you will find throughout this document, advocates frequently support people with disability in legal matters, whether supporting them in a tribunal process or in other ways.

At the February 2021 hearing on the experiences of people with cognitive disability in the criminal justice system, IDRS [Intellectual Disability Rights Service] Executive Officer Janene Cootes explained their approach to legal advocacy:

"I think one of the features of the way that we felt was important to do this work was to build a person's capacity, and a big way of doing that was to involve them in the decision -making. Too often in court processes, decisions are made for people, but the more somebody can learn the way things happen and make their own decisions and have their decision respected, I think that makes a very big difference to how the person goes forward and to their skills to cope better and do better."⁹⁶

⁹⁵ See Family Advocacy (2022) *Submission to the Department of Social Services (DSS) on the National Disability Advocacy Framework (NDAF) 2022-25*.

⁹⁶ Hearing on the experiences of people with cognitive disability in the criminal justice system - Transcript of proceedings - Day 7, Thursday 25 February.

Advocacy organisations have also contributed to competency and capacity building in the legal sector:

“...one of the recommendations from the UN was that all police, lawyers, magistrates, everybody have disability training and it absolutely needs to happen because we do support people through the legal process and that's because solicitors largely don't know how to talk to people. And so people can't make an informed decision about their legal issues because they don't actually understand what their choices are because of the way that the legal fraternity communicates with them.

I think we've built the capacity of a number of law firms over the last few years, and so they're our go-to solicitors and they've done a fabulous job in modifying their language and making sure that people are actually understanding information. But again, where is the proactiveness in terms of where is the money to do that? There's been a lot of time and effort working with those firms and with clients over the years to get them to that stage. But the court process is so inaccessible to people. They don't understand what's happening when they get there. Half the time they can't hear because it's just the way that the courts are set up. It's really inequitable for people.”

TAS Advocate, November 2020 Zoom workshop with DRC

“We've experienced a similar thing where a lot of our clients are finding, like, communicating with lawyers to be extremely difficult as they're not necessarily willing to, kind of, make the effort or are not trained in how to actually communicate with people with disabilities and often times the lawyers will get frustrated and either not act in the most optimal way, or withdraw completely because they're unable to communicate with the client.

I've had an example where the lawyer themselves was actually trying to do so by communicating through a third party at the client's direction and the lawyer was then charging the client double for that time. So they would charge for the original communication with the client and then the client would need the information communicated to their third party so then it could be explained in proper, understandable terms to the client and then the lawyer was charging them for that again, which didn't seem very fair to them at the time, and we've actually made a submission about that one a few months ago. So yes, there's definitely a lot of problems, and there seems to be a very large gap in the support system for people with disability to engage in not just criminal justice legal services, but just legal services in general.”

TAS Advocate, November 2020 Zoom workshop with DRC

“...there's just such a huge reliance on literacy, isn't there? So whenever I've had anything to do with the legal system and when I've been supporting people, a lot of it has been about being a point of contact because everything is via email now. If you don't have literacy, if you

don't have an email address, and if you don't understand what the next step is or why it might take a little while, then that's an access issue. That's massive, it's really massive.

And I guess the other thing is...just being there to be able to reframe or interpret for people so they can have a really clear understanding, and also having no skin in the game, saying do you need five minutes time out for people to know that they have time to consider their options and to be able to think about things.”

TAS Advocate, November 2020 Zoom workshop with DRC

Given the criminalisation and overrepresentation of First Nations people with disability, confirmed by hearings of the Royal Commission, FPDN [First Peoples Disability Network] has proposed a legal advocacy specialisation under the new National Disability Advocacy Framework focused exclusively on the cohort of Aboriginal and Torres Strait Islander people with disabilities in Australian prisons, to be co-located within Aboriginal Legal Services.⁹⁷

See more discussion of problems with justice processes in Section 12: [Criminal Justice Systems](#).

Systemic Advocacy

Systemic advocacy is when groups or individuals are working for long-term social change to make sure legislation, policies and practices support the rights and interests of all people with disability.

“My area is systemic advocacy. We've been working in this area, working personally, for more than 20 years in systemic advocacy. I'm finding quite a lot of issues we put up on submissions in relation to neglect and abuse and discriminations, and we find that there is no auditing system, the Government is funding and the funding is actually being reduced, funding in this sector, when we know it's a very important crucial service that is offered under the systemic advocacy.”

WA Advocate, April 2021 Solutions focused workshop with DRC

“...a point about preventive systemic advocacy - I think probably looking at my files, if I could put a systemic file for every client I probably would... like, for example, someone comes to me with a communication issue and then we identify they haven't had an aged care assessment, and then when I'm talking to the communication provider, there's just no access for people with disabilities, and then I'm putting a systemic issue to them and trying to get

⁹⁷ First Peoples Disability Network (2022) *National Disability Advocacy Framework Submission to the Department of Social Services*.

that changed within the provider so that for other people in the future they will never have to use an advocate to resolve this issue, the provider can resolve it themselves.

I think that the role of systemic advocacy is so important in this sort of prevention of abuse and neglect, and if we just had more time and more funding for systemic advocates, that would be amazing because we've got all of these clients that have crisis issues. And if I have the time, I can put together these files, but they're really time-consuming... but I think systemic advocacy is just so important."

SA Advocate, April 2021 Solutions focused workshop with DRC

Because systemic advocacy organisations, including disability representative organisations, are primarily focused on 'changing the systems', and attitudes and culture underlying the drivers of violence, abuse, neglect and exploitation, their main activities are primarily focused on preventative or corrective safeguarding. However, these organisations also frequently build community capacity and strengthen relationships among people with disabilities and the broader community, through creating resources, building human rights literacy and awareness, and facilitating networking and peer support. This contributes to stronger informal safeguards in the lives of people with disability.⁹⁸

Peer support

A peer support network is where people get together as equals to provide support to each other because of similar experiences or circumstances in their life. There is evidence that peer support can help people feel more confident, knowledgeable, capable, and less isolated.

Many advocacy and/or disabled people's organisations run peer support networks that empower people with disability. This may be in the form of self advocacy groups (see above) or through some other network or group focused on age, gender, disability type or other characteristic or interest. They may also include "self help" groups or local association networks focused on a particular disability type, health condition or diagnostic grouping. Such networks or communities of people with disability foster mutual support, personal growth and community involvement, and also facilitate education, information-sharing, and networking on the "grassroots level".

In late 2014, National Disability Insurance Agency (NDIA) appointed JFA Purple Orange as the national support agency for the Disability Support Organisation (DSO) Capacity Building Initiative. JFA Purple Orange created the [Peer Connect website](#) to support the work of 18 membership-based agencies in developing peer support networks. However, this selection of 18 funded organisations did not cover all jurisdictions and inconsistently covered disability types with a range of organisational models included. A review by the Social Policy Research

⁹⁸ See [Appendix C: Developmental domain](#) for more examples of how advocacy organisations engage in developmental safeguarding work.

Centre identified gaps in peer support delivery.⁹⁹ This early approach to funding peer support appeared to underestimate the labour-intensive nature of establishing peer support networks and the need for ongoing support to maintain their operation. Peer support now seems to be funded through ILC [Information Linkages and Capacity Building] funding rounds which are generally project focused and time limited.

The nature of project funding, in the absence of reliable and ongoing core funding, means that online resources (including many informational websites created since the introduction of the NDIS) cannot be kept comprehensive, accurate or up to date, and that peer networks established and grown may dwindle again, after the project ceases.

Supported Decision Making

Advocates often referred to value of supported decision making training in building the capacity of people with disability and thereby preventing and reducing abuse, violence, neglect and exploitation.

“Supported decision making is so important and if we had more funding for this it would certainly help in preventing abuse and neglect by having this readily available. It is really hard to get this support for our clients and even harder in our rural areas. If we gave people an opportunity and took the time for them to communicate their own needs, it would be really helpful.”

VIC Advocate¹⁰⁰

Advocacy organisations, and especially those who run Self Advocacy training and/or groups, have been at the forefront of developing and delivering training in supported decision making. This type of training and skills development can be particularly relevant for people with disability who are most at risk of abuse and neglect. (See Section 10: [People who need additional support](#) and Section 12: [Lack of choice and control](#).)

Advocacy organisations have also delivered training in supporting people to make decisions and enabling the model of supported decision making to be used in service and family contexts where substitute decision making (like guardianship) has often been relied on and over-used.

One advocate calls for there to be a focus on *“funding for supported decision making and other safeguarding mechanisms in NDIS plans”*. (See Appendix A: [Advocates voice their ideas for improvement](#)).

⁹⁹ Social Policy Research Centre (2019) [NDIS Peer Support Final Report \(unsw.edu.au\)](#)

¹⁰⁰ VIC Advocate, "Advocates Zoom In On... *Safeguarding rights and wellbeing*", December 2020 Zoom discussion

Other forms of education and capacity building

“Advocacy assists people to prevent harm by teaching them about their rights, sharing information about mechanisms that protect people (e.g. Circles of Support and other methods for surrounding the person with unpaid, committed supporters), and linking people with information and services that can assist them to access their entitlements (e.g. Social Security Rights Victoria).”

VIC Advocate¹⁰¹

“Primary prevention in the form of community education is essential to begin the process of changing attitudes about violence and abuse. It is important to ensure that people understand their rights and have support to have their rights championed. Advocacy is a critical aspect of educating and supporting people to access their rights.”

NT Advocate, April 2021 Solutions focused workshop with DRC

The independent advocacy sector is connected to and often overlaps with the organisations and networks that drive education and capacity building to strengthen informal safeguards for people with disability.

Since the rollout of the NDIS, there has been considerable uncertainty in how these activities (including peer support and supported decision making) are resourced and maintained due to community organisations largely relying on securing NDIS ILC funding for projects.¹⁰²

Forms of capacity building across other parts of the community sector and other service systems include:

- managing money, budgeting etc;
- financial counselling or advice;
- cooking skills and nutrition;
- parenting supports;
- relationships education;
- consent and sexuality education;¹⁰³
- sexual health and family planning supports;
- parenting courses;
- health and mental health consumer rights, responsibilities and representation;
- community legal education;
- welfare matters;¹⁰⁴

¹⁰¹ DANA's 2015 Quality and Safeguarding Survey - Response from VIC Disability advocate. For discussion of 'circles of support' and microboards, see Section 10: [People who need additional support](#).

¹⁰² See discussed above in relation to [Peer support](#).

¹⁰³ [Sexual Lives and Respectful Relationships \(SL&RR\) | Institute for Health Transformation \(deakin.edu.au\)](#)

¹⁰⁴ e.g. [DSP Help](#) website created by Social Security Rights Victoria.

- tenancy rights and responsibilities; and
- consumer matters.

Often advocacy organisations have used project funding to adapt and deliver these types of capacity building directly to people with disability through their established networks.¹⁰⁵ For instance:

“PWdWA has sought additionally funding to run community education under grants such as the Information, Linkages and Capacity Building grants. We believe that this type of education should be a core ongoing function of advocacy.”¹⁰⁶

In addition to developing their own training programs and resources, advocacy organisations have also been active in helping other community organisations (or sometimes academic institutions or government agencies) to build or modify their training or resources to be more accessible and supportive of the needs of people with disability.¹⁰⁷

Inclusive Schooling

One advocate explained how inclusive education contributes to the natural safeguards people experience during their school years and beyond:

“It seems pretty obvious but, what measures do we need to prevent violence, abuse, neglect and exploitation, we are advocating for inclusive education. And it seems really obvious, but the fact that we have to say it out loud, by being included at school, it's almost like a multiplier of rights, in a way. [By] having a proper education, obviously the research shows that you are more likely to be included in academia, socially and with curriculum. That leads to better outcomes in the longer term: more likely to finish secondary school, more likely to finish tertiary education, more likely to get employment and more likely to live independently. These factors provide natural safeguards and protections because people are being seen in society, not being segregated and taken off to the corner room... You know what I'm saying. I guess it's the multiplier of rights that ultimately leads to the other rights we talk about (workplace, housing, being a citizen that can participate in the political sphere); it is the gateway to the ultimate natural safeguards for protections from abuse and neglect. It leads to a stronger community, stronger health for everybody, because wellbeing is another by-product of that, when you feel like you belong. And if you can participate economically, that leads to a stronger economy as well. It has a lot going for it, we just have to make all those barriers come down...”

NSW Advocate¹⁰⁸

¹⁰⁵ e.g. Advocacy for Inclusion (2014) [Self-Advocacy & Nutrition - YouTube](#); Action on Disability within Ethnic Communities (2020) [Skin Care Routine - YouTube](#) and [Mental health and self care - YouTube](#)

¹⁰⁶ People with Disabilities WA (2021) *Submission – Issues Paper: Safeguards and quality*, p29.

¹⁰⁷ See many of the relationships and violence prevention resources listed on this page of the DANA website: [Resources – violence and abuse | Disability Advocacy Network Australia \(dana.org.au\)](#)

¹⁰⁸ NSW Advocate, "Advocates Zoom In On... Access to Education", November 2020 Zoom discussion

Section 6: Independence, choice and control for people with disability¹⁰⁹

In general, advocates express the view that upholding the maximum independence, choice and control of people with disability will contribute positively to safeguarding efforts.

Similarly, implementing safeguards like ensuring access to independent advocacy and ensuring provision of capacity building and training in human rights awareness, supported decision making and self advocacy for people with disability, will contribute to independence, choice and control.

Although scenarios are imaginable in which regulations to keep people with disability safe may restrict their autonomy or choices (for instance, by preventing them from choosing a harmful service provider) the values of independence, choice and control are largely not in tension with or needing to be balanced against, promoting the right to live in freedom from violence, abuse, neglect and exploitation. Rather, these values strengthen one another.

For the most part, efforts to uphold independence, choice and control in service contexts contribute to the quality of services and safety of people with disability. (see [Section 4: Features of quality services](#) above)

Section 7: Independent monitoring and oversight¹¹⁰

Advocates described a range of service settings they see operating with limited oversight or active monitoring for signs of abuse, violence, neglect or exploitation.¹¹¹ They also spoke of people with disability who struggle to speak up and/or are not listened to when they raise issues about mistreatment or poor quality supports:

“I believe what's missing is there's nobody measuring this stuff. So if you look at the values that the NDIS or NDIA talk about, if we look at just basic human rights, nobody is measuring this for people in CRUs [Community Residential Units] and I think that if that was literally

¹⁰⁹ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p6. Question 4 asked: “What can be done to uphold independence, choice and control for people with disability when implementing safeguards against violence, abuse, neglect and exploitation?”

¹¹⁰ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p6. Question 6 asked: “What role does, or should, independent monitoring and oversight play in safeguarding the right of people with disability to live free from violence, abuse, neglect and exploitation? Should the NDIS Quality and Safeguards Commission be taking a more active role in ensuring service providers are adhering to the appropriate standards, particularly during the pandemic crisis?”

¹¹¹ See [Attachment B](#) – *Advocates on Quality and Safeguarding* – April 2021.

measured and quantified, people would be horrified at what the data would tell us. So if there's nobody picking up that work, I just think we just keep talking in circles and no real significant change could happen. It's a very complex issue. There's complexity for the providers, there's complexity for the actual support workers, but nobody is actually measuring the outcomes for these individuals."

VIC Advocate, February 2021 Zoom workshop with DRC

"...from our experience, we're finding that [Quality and Safeguarding Commission is] in the favour of the service provider rather than the participant. It's educating and hand-holding and they forget that there needs to be compliance and there's nobody coming and actually checking from the Safeguards Commission, to actually visit the person and actually spend some time actually getting to know what the issues are and what's going on in the houses."

VIC Advocate, February 2021 Zoom workshop with DRC

"For so many people in group homes and go to day programs - they have no one in their life outside of a closed service system. If everyone in the service system agrees on the quality of the person's life, it takes for them to have 'behaviours of concern' to be able to protest. It means that people who don't protest may be incredibly unhappy and no one recognises it. The lack of outside people, or connection [to] the community is a huge problem... There needs to be monitoring of quality of life - and it has to be external and independent."

VIC Advocate, February 2021 Zoom workshop with DRC

"The Issue is that ...Education/NDIS and Aging are self regulated - No outside bodies with any real power. These organisations don't have to change because no one makes them."
NSW Advocate, March 2021 Zoom workshop with DRC

"...there are significant limitations with worker screening that can mean problematic workers move between organisations".

QLD Advocate, April 2021 Solutions focused workshop with DRC

Advocates also expressed concerns about current processes allowing for internal investigations, in allowing intimidation, bullying and reprisals or other actions to cover up what has happened:

"...One of the biggest problems I find, when I look at a group home situation a couple of years ago, the client could articulate some aspects of abuse by staff, but couldn't necessarily pull the whole picture together. So we had fragmented pieces of information, but there was a basis to that. Within the service, we were investigating, but we were also detecting an

undercurrent of bullying from the perpetrator to other staff. The issues don't go anywhere, and in the meantime, whilst that staff member who had accusations made against them, while investigations were against them... the investigation [might be] shut down by bullying from the alleged perpetrator to other staff – it [might be] shut down due to communication difficulties with the person with the disability. But the service itself is doing the initial investigation. And then, if you do get to the Quality and Safeguard Commission, sometimes you hear language like 'Well, it depends what the others view has taken place.' You are not always finding that they are using the power that they have, and the authority that they have, to actually do something about this. In the end, people don't complain, because they won't be believed or other residents in the house see what happens when one person spoke up.

I am just feeling that I don't think the service themselves should be investigating this, [and changing this] would remove some of that component of bullying, remove the ability for staff to do some of that. We saw what happened with Yooralla - other staff members were silenced, victims were silenced. It is still happening. There has to be a better way for some to have systems and safeguards in place, but I don't necessarily believe that they are working effectively. And when they start work, it is when untold horror has unfolded against multiple people.

I would have thought that after the Yooralla issues in Victoria, that this would be addressed and people would pay attention. But, two years later, this is still happening... So what they do is they've moved the person with disability away from the house, away from the family, from one side of Melbourne to the other side of Melbourne, because they said his behaviour was unacceptable. His behaviour is unacceptable because he is in house where he feels unsafe. And the cause of that feeling is still there. That house, anyone associated with that house or that service, must not do the initial investigation. I think that is a good starting point. I don't know what other things. I think we need some answers to this, and if we see good practices, it would be great to hear about them.”

VIC Advocate¹¹²

“...with regards to gaps, I'm drawing on one case here so it might not be true generally but with regards to the Quality and Safeguards Commission, my impression is that most of the dialogue... if there's a complaint or reportable incident, that it is between the service provider and the agency. So the service provider has the opportunity to control the narrative, so to speak, and it seems as if there isn't ... a proper investigation, at least according to this one case. Not reaching out to the family and doing site visits to speak with the participant, the client, whoever made a complaint, that is really a lack of proper information gathering to understand what is going on, and they're taking too many cues from the service providers. 'We've heard there is this complaint, can you develop an action plan?', and then the service provider can come back and say that 'yep, we developed this action plan, we're going to do

¹¹² VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

this training module'. But in the circumstances I'm thinking about, there was abuse occurring behind the scenes, it went unnoticed. I knew about it because there was video evidence that wasn't submitted to the Commission so nobody from the Safeguards Commission really ... They showed their impotence because they didn't do site visits, they didn't really speak to anyone else except the service provider. I think that's a danger. They really need to exercise the powers that they do have.

And they place the onus on the service provider to communicate to the rest of the care team and family members and they are not necessarily doing that if they have something to hide. And I guess generally it's not so much a gap, but in terms of a safeguard, a no-brainer is ensuring that allied health and support coordinators are not from the same service provider as the SIL [Supported Independent Living] or the SDA [Specialist Disability Accommodation], just to have that independent set of eyes. Advocates will not always be involved. There aren't enough of us. That's potentially another way to get a true sense of what's going on."

VIC Advocate¹¹³

"...just in relation to the Quality and Safeguards Commission, it would be good if [the Disability Royal Commission] could make some recommendations because at the moment it does seem very compliance based and process oriented rather than being actively preventing abuse and neglect, which is part of its terms of reference, so looking at improving the complaints process so that it doesn't feel like you're looking into a black hole...."

NSW Advocate, April 2021 Solutions focused workshop with DRC

"...in regards to the workforce, where are the real checks and balances in this sector? We have the Safeguards Commission and in Victoria [there is] the Disability Worker Commission, but my experience of them, and again speaking with colleagues, has been extremely disappointing, very slow moving and in some cases, actually add to the harm and the situation because of their lack of response or their... yeah, one situation I'm working with, we're now four months down the track and the investigation still hasn't been completed and the lead investigator is not returning my phone calls and not responding to my emails.

So we have these things in place, but they are not effective, they are not actually supporting people with disability. I'm sure there are experiences where they have, but that's been my overwhelming [experience]... yes, both with National Safeguards and the Disability Worker Commission, they don't seem to have any real teeth.

¹¹³ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

And then... yes, concerns about the workforce and the level of skill, effective education and training and then leadership, such a lack of oversight in so many scenarios where there's one-on-one sole providers, even in large organisations."

VIC Advocate, April 2021 Solutions focused workshop with DRC

Advocates also pointed to gaps between monitoring services for having compliant policies and procedures versus what happens in practice on the ground:

"...there's some models out there that [have] a very big gap between the boots on the ground to the management. So the manager might manage five houses, but there's no one actually on the ground, actually working with the staff, actually giving that sort of mentoring or that sort of leadership to make sure that things are happening

...There's not a lot of consultation I don't believe with the staff with their management. Management have it all perfectly written out. They have it all detailed, everything looks wonderful on reports, but the staff on the ground have no idea these things are in place and there's no communication down below.

So it all looks wonderful up the top, and when you make a complaint to the Quality and Safeguards Commission, it all looks wonderful to them because everything is ticked off and it looks like a neat little package. However, realistically and in reality, it's not happening. Why would people make a complaint if things were okay? If it's not investigated, then there's no point.

... there is no reason, there is no purpose for the Quality and Safeguards Commission. We thought as organisations, and people with disabilities that I've spoken to thought that, this was a really good win and it was great, they were going to have some teeth, they were going to actually be on the side of the person with the disability, and they were actually going to dig up things, and actually get things right and fixed. But it's actually not happening. It's completely the opposite. It's, "Oh, I'll need to send off to the organisation or the service provider and find out what they're doing about that" and then they send back all in their nice little neat package, "Yes, we're doing all these things", but on the ground it's not happening at all and the staff often don't even know what is even... what they're supposed to be doing either.

That's a big gap to me. ...I'm sorry, but there's a lot of dishonest people working in these fields [where] there is no accountability at all. It's disgraceful."

VIC Advocate, February 2021 Zoom workshop with DRC

"...As a private citizen, I was going to the supermarket, drove past a group home that I, as an advocate, knew was a group home, witnessed abuse, went in, knocked on the door and I

was... a complaint was made about me, so I diffused the situation, ensured the client was safe. A complaint was made about me because I did not ring the office and make an appointment to go to visit that home.

Now, when you've got a provider who has that sort of attitude, that actually 'we don't welcome anyone to visit these homes because we want to make sure everything is squeaky clean and people are...' before they enter, I think that's a perfect example of 'we can't just wait and be invited' - there needs to be stronger safeguards."

TAS Advocate, April 2021 Solutions focused workshop with DRC

Advocates also spoke at length about current frameworks being ineffective to monitor the quality of behaviour support or the use of restrictive practices by providers:

"...in relation to restrictive practices, if we happen to, either in an SRF [Supported Residential Facility] or segregated setting, if we do happen to observe that and we're concerned about it, you can take it up with the organisation and often that's really tricky because they will always have a reason as to what you might have observed or heard from your client or the person that you're dealing with. We can report those things to the Quality and Safeguards Commission. Again, from my observations of what they do, they take it up with the organisation and then they will accept an explanation as to what's occurred. We can feel really limited, and I'm not sure how other advocacy agencies deal with that in terms of getting some action in relation to those restrictive practices that we do observe."

SA Advocate, December 2020 Zoom workshop with DRC

"My experience with them is that you have to actually hound [the Quality and Safeguarding Commission], and repeatedly, to get them to do anything. They don't seem to feel any obligation whatsoever to get back to the complainant and tell them anything. The complaint goes in and then all of the activity after that is behind the scenes, presumably by some service provider, but you don't get told anything that happens after that unless you chase and chase and chase, make complaints, escalate, make more complaints, but even then, the latest that I'm getting ...is 'it's gone to our compliance team'. Okay, well, it's been there since September. What does that mean? What are they doing? What's happening? What is that? Nobody from the compliance team will talk to us. I don't even know who the compliance team is. Nobody will tell us what's [happening behind the scenes], that's effectively the end of it.

It's gone to a complaint to the Commonwealth Ombudsman. They're not getting any answers. It's just a big black hole. And I just have to question what's the purpose of a process that does that? The person making the complaint has had no outcome whatsoever, no communication back. Why bother?"

VIC Advocate, February 2021 Zoom workshop with DRC

“The NDIS QSC [Quality and Safeguards Commission] is drastically understaffed and does not have the resources to monitor behaviour support providers/practitioners and the adequacy of behaviour support plans.

The biggest barrier is insufficient funding of NDIS QSC and OPG [Office of the Public Guardian]. NDIS QSC needs to have sufficient funds for ALL PBSPs [Positive Behaviour Support Plans] to be properly vetted, and for the work of ALL behaviour support practitioners to be properly monitored. This includes monitoring of whether statutory time frames for completion of IBSPs [individual behaviour support plans] and CBSPs [comprehensive behaviour support plans] are met and of whether the BSPs meet the criteria in the NDIS Behaviour Support Rules.”

QLD Advocate¹¹⁴

(Refer to the next section for more discussion of Quality and Safeguard Commission staffing and processes)

Advocates often described community visitor and official visitor schemes (where they exist and are active) as a valuable external oversight and endorse the introduction, expansion or strengthening of visitor schemes and their reach. (See Appendix A: [Advocates voice their ideas for improvement](#))

“There are some good stories of change in the reports of the Community support visitors. ...good news of the impact of community visitors... [After a report of a group home restricting access to finances] ... I went looking for what happens with the community visitors scheme and found a report that they apparently put out at least annually. I think it's an annual report and I just read through that and there's some very good stories in that about where that's been helpful. Very interesting statistics on that and me going, "Oh, that report also seems to highlight huge gaps in how many services actually get visited and how many issues don't necessarily get resolved." But it's an interesting read and it's something that's outside my scope but I think it would be good for the Commission to be looking at.”

NSW Advocate, March 2021 Zoom workshop with DRC¹¹⁵

“...what I'm hearing about looking at community visitors, et cetera, is that probably a lot of us feel like the safeguarding mechanisms that we currently have are probably not strong enough, or effective enough, and the fact that it's not done in a kind of outreach model, that it's very much a 'you come to us' inaccessible model for people with cognitive disability. I think having a huge amount of work... policy work and remodelling of the safeguarding mechanisms we have is really, really important to make sure that safeguarding actually outreaches into the

¹¹⁴ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

¹¹⁵ See NSW Ageing and Disability Commission (2019) [Official Community Visitors Annual Report 2018-19 \(nsw.gov.au\)](#)

community and into all settings, where it's not just a sort of inaccessible phone number, but actually they're going into group homes, prisons, closed settings. That's a really important thing that really, really needs to be strengthened I think".

VIC Advocate, April 2021 Solutions focused workshop with DRC

One advocate questioned their effectiveness in prompting long-term positive changes:

"You know my experience with the official visitor scheme is, they come in...which is really great, and they're very responsive and really across all the issues, and it gives the provider a good scare, but that's it. Yeah, just a scare. ... doesn't actually change behaviour."

ACT Advocate, October 2020 Zoom workshop with DRC

There was varied experiences and uncertainty as to how often visitor schemes refer people with disability to independent advocacy organisations for ongoing support.

"[Our organization] has never received a referral from a community visitor."

NSW Advocate, March 2021 Zoom workshop with DRC

"I think also to make people aware and strengthen the role of the Official Visitors Scheme, we have had a number of referrals through them for advocacy support."

ACT Advocate, October 2020 Zoom workshop with DRC

PWDWA recommended in their submission on Safeguards and Quality that the State of WA introduce a Community Visitor Scheme.¹¹⁶

Section 8: Improving laws, practices and policy frameworks¹¹⁷

Advocates perceive considerable room for improvement in relation to complaints and reporting mechanisms and ensuring that independent advocacy support (which some people

¹¹⁶ People with Disabilities WA (2021) *Submission – Issues Paper: Safeguards and quality*, pp27-30. Also see Connor, S., & Keely, B (2015) *Behind Closed Doors: Preventing violence, neglect and abuse against West Australians with disability*. Report by People with Disabilities WA & Developmental Disability WA, p91. Recommendation 5.

¹¹⁷ Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p6. Question 3 asked: "How could safeguarding laws, practices, or policy frameworks (including the NDIS Quality and Safeguarding Framework) be improved to better prevent, reduce and respond to violence, abuse, neglect and exploitation of people with disability? We are particularly interested in Australian and international examples of good practice."

with disability may need in order to initiate or pursue a complaint or report mistreatment) can be accessed by everyone who needs it.

Ensuring accessibility and integrity of complaints mechanisms

Advocates described current complaints mechanisms as inaccessible, confusing, ineffectual and/or weighted against people with disability:

“What is really evident with the Safeguards Commission is the power imbalance. The preferred outcome for the Safeguards Commission is a negotiated agreement. They mediate or they come up with some kind of agreed resolution between the person who has made the complaint and the service provider, and all of this kind of stuff.

The power imbalance in that... in that so-called agreement, is just not addressed. So the person who is most vulnerable, can be almost forced into agreeing to whatever the service provider puts forward as their preferred resolution. I think that is, again, one of the biggest failings for the Safeguards Commission. That power imbalance is not even acknowledged, let alone actively... There is no active work done to try to rebalance that between the client and the service provider. I think that is what happens... People get forced into making agreements that don't necessarily address what is happening for them.”

VIC Advocate¹¹⁸

“Complaints are addressed in an adversarial fashion, similar to that of our legal system. Thus, the complaints are easily dismissed because the burden of proving the validity and appropriateness of the complaint is placed on the complainant, who is already at an extreme disadvantage.

Clients need to be provided with an easily accessed, clear and meaningful way to speak about what they need and want. This voice must be considered as the fundamental core that all actions are accountable to.”

QLD Advocate¹¹⁹

“One of the barriers to making complaints is the incredible inaccessibility of the NDIS Quality and Safeguards Commission (QSC). How would a person with intellectual disability actually go about making a complaint? In most cases, they cannot do it independently as they may not have the phone number, may not be able to use a phone and may not have safe and private access to a phone. In that case, they rely on paid service providers to make complaints with them. What we have seen in advocacy, though, is that service providers are incredibly

¹¹⁸ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

¹¹⁹ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

reluctant to support clients to make complaints and, instead, view it as an advocacy issue. We frequently respond to service providers to tell them that they have a duty of care to their clients, and also play an important safeguarding role in supporting clients to make complaints.

...This client ...chose not to make a complaint to the QSC because he was not able to understand who they were and what the point would be in doing it. He also felt very angry with NDIA at that time and could not understand that the QSC were a separate entity (and really, how reasonable is it to expect people to understand that, when they look exactly like the NDIA?).

The other significant barrier I have found in making complaints to the QSC, is the lack of knowledge and skill of staff at the QSC. It is difficult to explain the problem to a staff member at the QSC if they are not familiar with RPs [restrictive practices] and how they intersect with state legislation. If they do not understand local legislation (such as the Disability Act in Victoria), they are not able to comprehend how a RP can go outside any framework or legislation but is not questioned because there is no one to question it. In one instance where I contacted the QSC, I stated that the client was not able to understand the complexity of the complaint about his service provider. The person from the QSC wanted to get his consent to go further but when she spoke to him, he wasn't able to understand who she was or why she was calling. He eventually said he didn't want to make a complaint.

...In one case that an advocate has been working on for more than 2 years, the client's lawyer made a complaint to the QSC which was ignored. The only way she was able to get a better response was to make a complaint about how the complaint process was handled. I have heard several advocates say that the only way to get an adequate response from the QSC is to make a further complaint about the process. This means that effectively people with intellectual disability will be locked out of the process, as they are unlikely to understand how to make a complaint about a complaint, even if they have got as far as making a complaint in the first place.”

VIC Advocate¹²⁰

Being able to guarantee the confidentiality of people's stories is very important:

“There's a sense of shame if someone has been abused by their stepfather, the mother may know. But there was a sense of shame in one family of bringing this issue up and going to the [Disability] Royal Commission and she didn't want it out in the public. She'd been through a process before. But it's being able to say to families that this is completely confidential and to be able to guarantee that I think it's really important and it will help people come forward.”

WA Advocate, November 2020 Zoom workshop with DRC

¹²⁰ DANA's 2020 *Restrictive Practices* survey, Response from VIC Advocate

"We have had these issues about educating staff for 30 or 40 years, with all the stuff that's gone on in Victoria, with that big disability service provider down there. We've had tons of Royal Commissions. We've had tons of Senate inquiries. It's all very well to say people should be educated but we have said the same thing for donkey's years and it doesn't happen. People, I think - it's probably a pessimistic view of human nature - many of them don't do things unless they're forced to do it. I would say, by the way, that I do think there are very many service providers out there that are very good service providers and do a really good job.

So the complaints we hear are with the troublesome ones, and that's where you need effective regulation. ...There's no point in saying we've got courts and we've got tribunals. When our clients who don't have legal capacity, and don't have funds, can't access them. There's no point in having regulators like the NDIS Quality and Safeguards Commission - or in New South Wales, with restrictive practices, now this Ageing and Disability Commission - if they're not actually given powers to hold regulators to account in individual cases. For 30 years we have had a complaints system that just says, "Give the complaint to the service provider; if they don't resolve it, maybe you can go to an Ombudsman". An Ombudsman has no power. They write a letter and say, "Well, this is what you should do", but you can't enforce it.

So unless you're going to actually give our clients legal rights, and I mean in a practical sense - where they can access a regulator who can hear the matters that are submitted for them, or perhaps on behalf of them by their parents or carers, or their advocates - and hear the case and make a decision in a very short time, which holds the regulator to account, you're never going to get change in this industry. It was set up to be privatised to make profits and, unless you're going to put in the legal machinery to make them accountable, it's never going to change. It's going to get worse.

...[Our organisation], we always try to settle things. I would like to settle things with service providers. What I am saying is when it gets nowhere, as a last resort, our clients have got to have somewhere where they can go and get a remedy, and they can't do that. That's what I am talking about. They can't get a remedy in the courts or the Tribunals or from the Commission, so we actually need for them, at the end of the day, as a last resort, to have a legal remedy where someone can say, "Yes, service provider, you were wrong there, you denied our client Community Access 10 times in a row because you wouldn't fix your bus, and that's not acceptable, so you've now got to give him back his 10 Community Access visits".

Things like that that can be fixed up. Or "you've let him" - these are all cases I've got, "You haven't fixed his toilet in his room for six weeks". Now, a tenant could get an urgent repay and pay for it himself and go to the Tribunal and get compensation back. In a group home, you can't. So you should have a regulator that can say: "Mr Group Home, you're at fault.

He's gone and fixed up his own toilet or he hasn't had his toilet for so long, bang, you pay him a fine or compensation of \$2,000", as a last resort, that's what you need."

NSW Advocate, March 2021 Zoom workshop with DRC

Leadership Plus calls for a complaint to be seen as:

*"a vital opportunity to minimise systemic risks and improve lives, rather than a tiresome blemish to be hidden and smoothed over..."*¹²¹

Ensuring access to independent advocacy for people with disability at risk

As the Senate Community Affairs References Committee recognised during the 2015 Inquiry, violence, abuse and neglect often thrive in institutional and residential settings, and people with disability experience significant barriers in seeking access to justice. Individuals who have been isolated and mistreated may struggle, not only to voice a complaint, but to even identify and recognise that what they have experienced is abuse, violence, exploitation or neglect. The Inquiry Report noted that one of the challenges for advocacy services is "having regular access to institutions and residential settings to assist people with disability in identifying and reporting abuse".¹²²

The Committee also expressed particular concern at evidence suggesting that people with disability are actively prevented from accessing Self Advocacy services.¹²³ This is consistent with many advocates observations of "gatekeeping" around people with disability in segregated settings.¹²⁴

Advocates discussed the major issues that continue to exist in ensuring that independent advocacy is accessible and visible to people with disability at risk, whether in service settings, closed settings or in private homes:

"...advocates need to be able to attend the home and have a relationship so that the people in the homes are not solely reliant on the staff that care for them..."

¹²¹ Leadership Plus (2021) *"Unsafe at an speed": A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability Re: Safeguards and Quality*, p8.

¹²² The Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, Final Report, p194.

¹²³ Ibid, 201-202.

¹²⁴ See Section 12: [Examples – Restrictive practices](#) for a Tasmanian scenario in which a person with disability is denied access to self advocacy activities as "punishment" for not following rules created by providers. See also [Segregation and isolation](#) and [Accommodation](#) below

They live in fear of discipline and not having someone else to speak to isolates them and leaves them to the mercy of their staff. Who do they complain to? The people who they look to for care and fail them?"

VIC Advocate¹²⁵

"Advocates... investigate allegations of abuse and can instigate protective measures to either relocate the person away from harmful situations or to advocate for improved supports, services, housing options. However, this can only occur when the person with disability themselves can be contacted and give consent and authority for the advocate to act, or a family member who has guardianship or recognised authority. Advocates can be hampered when an allegation of abuse or exploitation or restriction and control is reported if the person either does not have capacity to give consent for the advocate to act or is in a situation where the advocate cannot gain access to speak with the person. It would be an improvement if advocates could call on more proactive investigative entities to determine the accuracy of the allegations."

QLD Advocate¹²⁶

"They have gone from you couldn't get a Citizen Advocate in, to their having a Christmas function and I asked how open that is? They said the more the merrier. I don't know why in two weeks suddenly it's not a risk to everyone, but one individual advocate was a risk to everybody. I think it was ...about the advocacy exclusion rather than COVID."

NSW Advocate¹²⁷

"One of the things I think we have all experienced is one of the difficulties of obtaining entry to some of the places. It's not like advocacy wants powers or anything, but it's the opportunity to being able to visit places like aged care homes, group homes, some of them have very closed doors and they don't want you coming into see. That's one of the barriers we have. You hear little concerns. You might have a support worker who says these things about the place and it rings alarm bells, but they won't allow you access to just go and say hi. So that's one of the barriers I always find... being able to even start the process to see if things are OK in some of these places, when they won't even allow you entry."

QLD Advocate¹²⁸

¹²⁵ DANA's 2020 Segregated settings survey, Response from VIC Advocate

¹²⁶ DANA's 2020 Advocacy and Abuse Prevention survey, Response from QLD Advocate

¹²⁷ NSW Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

¹²⁸ QLD Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

“...in group homes, and any other place as well, the advocates need to be in there regularly to get to know what is happening, as well. It can't be the one off “pop in” every so often, there has to be a relationship and understanding of what is happening with that person. And that is often outside the time and resources of advocates to do that stuff.

They are called in at crisis points [rather] than ...they are just [there] as part of the everyday functioning of a person.”

VIC Advocate¹²⁹

“...in terms of general access of advocates into prisons, I don't think prisons promote disability advocacy services. We do get contact from prisons, but it's really hard to get in contact with people in prisons. It's really hard to be able to facilitate that support, and a lot of the stuff that's come through, that we have got, most of it is around issues with NDIS and getting appropriate supports within the prison.”

WA Advocate, October 2020 Zoom workshop with DRC

“...where a SIL [Supported Independent Living] has such strict access to the premises that you have to request two weeks prior to the appointment and you're not necessarily guaranteed access. ... Or you have to arrange to meet them external to the premises. It's something that occurred, that started about a year ago here ...basically around controlling, like attempting to control... the ins and outs of those group homes. At first ...we thought it was like a safety thing for the clients, but then it can be used to restrict the client from communicating with their advocates or with their coordinators of support.

...So most of the clients that this would apply to, they don't have capacity to use their hands, or they have limited capacity to use their hands [to talk on a phone], so what we've relied on is just showing up to see them or they'll have a hospitalisation and the hospital will contact us and then we'll go down and visit them at the hospital. Or we make the application to go visit and then we're able to see them.”

NT Advocate, November 2020 Zoom workshop with DRC

“... people who are most likely to be under restrictive practices, they don't get access to advocacy. I mean, we are advocating for people who are under restrictive practices. That's come to us because it's a complex matter, but we have limited capacity to take those things up, as I know that all advocacy organisations do.

¹²⁹ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

But if there hadn't been a person in that person's life who was an ally and able to stand up and say, "This is wrong" and then they've contacted advocacy - I think there's only probably one person and the other people might be able to... I can only off the top of my head think of one person we advocate for that's subject to restrictive practices that referred themselves - and I think any other person we advocate for has come via some other method, and typically that would be... not a service provider, it would be a family member often."

SA Advocate, December 2020 Zoom workshop with DRC

"One of the issues in terms of the Disability Royal Commission is that access to people who are experiencing restrictive practices. ...we've had difficulty accessing people in supported accommodation settings to tell their stories because the service providers do act as the gatekeepers and I think they would have concerns about issues that might be reported by residents."

SA Advocate, December 2020 Zoom workshop with DRC

"...we only see a small fraction of the restrictive practices out there. A lot of these occur in settings which we either don't have access to or people aren't able to access us."

NSW Advocate, March 2021 Zoom workshop with DRC

"I was going to speak to the issue about some of the barriers to making complaints, and in my experience, people that are under a public guardian can have difficulty sometimes accessing a disability advocate to even get that assistance, to perhaps try to put in a complaint or bring about change. And I think that's a real barrier that needs to be addressed and recognised by the Royal Commission - some of those practices at the Public Guardian, that in some situations they can deny a person access to an advocate citing privacy reasons, or deny the advocate access to any of the person's allied health professionals or support teams that are going to be key to them working successfully with the person."

QLD Advocate, December 2020 Zoom workshop with DRC

"The Public Trustee here in [QLD city] won't allow an advocate to go in with ...her protégé to do a will... because in general, whether it's a public trustee, public guardian, service providers, they do not understand the rights of people to have an independent advocate. They just don't get it, even though it's in the NDIS Act.I don't think (service providers, government, NDIA, etc.) really feel comfortable with someone announcing themselves as an advocate. They want some proof of their bona fides, and I can understand that, but we've got to grapple with that because, at the moment, I think we're seen as being part of the fringe, not the mainstream. We're not seen as the right of anybody. I guess I'm on my little soap box

here, but I think the Royal Commission needs to hear from advocacy programs of every model.”

QLD Advocate, December 2020 Zoom workshop with DRC

“OPG [Office of Public Guardian] often think that their appointment means that advocacy is a service and they tell people they don't need an advocate. We have taken this up with the OPG but they say that advocates need to escalate this by complaining to the relevant regional manager.”

QLD Advocate, December 2020 Zoom workshop with DRC

“I was just going to say that unless the workers, or the organisation, or the service provider with the day services, is actually going to offer advocacy and actually explains to people that they can access advocacy, then it's controlled by the “dog at the gate”. They're not going to. I find organisations that invite advocacy in - I think that's transparent and it can be a very good thing. It can be a ...working collaboratively with. But I find that very few and far between, especially with day services. They're very protective”

VIC Advocate, February 2021 Zoom workshop with DRC

“...there is a reasonably well-known provider... and when we've attempted to have conversation with them or gain access to someone that we can see is potentially finding their experience there difficult, it's been hard to do so. There has been a resistance there.”

“...I have had people who are in positions of management in supported accommodation saying, “I didn't know that the people living here could have an advocate”, as well as people who are resistant to the idea because they know that the things that they do and put in place are going to be looked at and checked up on. So there is a resistance to that.”

“... it's about introducing the ability to have that independent input from someone in a person with disability's life who is segregated or doesn't have that. So greater access to advocacy. And that's where it does sound self-serving, but it's not - because we're the ones that see the difference that is made to people's lives once they do engage with an advocate. That would be the biggest thing that I can think of at the moment, as well as significant changes that are required to the NDIS...”

NSW Advocate, March 2021 Zoom workshop with DRC

“In our service, the person with a disability is the person we provide advocacy for. How I ensure I am working in the best interests of the person with a disability is to involve them in

every step along the way to the extent that this is possible and to explain to the person potential outcomes for them to any decision they are making. All our clients are told not only what they may choose to do or not do and the potential circumstances of those decisions, but also their rights regarding changing their mind and withdrawing and that they can contact our service again to get more advice in the future. In many circumstances though, my advocacy, it is on behalf of that person under the direction of a parent or carer etc. This brings the challenge of always questioning is this in the best interests of the person/child.”

NSW Advocate¹³⁰

“...there's no legal right of an advocate and I think that that is problematic when you're endeavouring to work alongside someone around some of these issues. So it might be about changing the legal rights of advocates...”

VIC Advocate, April 2021 Solutions focused workshop with DRC

In relation to the role played by advocates in preventing violence, abuse, neglect and exploitation of people with disability:

“a bigger role could be established, if there was commitment by supported accommodation providers, child protection, Australian disability enterprises etc... ensuring an advocate's presence, where an advocate can discuss rights in a supportive, prolonged environment, building relationships with people that may face more barriers than most, to understanding their rights or having someone on their side.”

VIC Advocate¹³¹

“We can increase the hours in advocacy, but it is not the only issue we have.

To have a centralised intake would or could be a disaster. We build relationships over time, trust with long term community members who might not call for help if they had to go through a massive intake call centre.

We have to network and make relationships within our community, with local councils, community health, hospitals etc.”

VIC Advocate¹³²

¹³⁰ DANA's 2020 *Restrictive Practices* survey, Response from NSW Advocate

¹³¹ QLD Advocate, "Advocates Zoom In On... *Advocacy & Abuse Prevention*", December 2020 Zoom discussion

¹³² VIC Advocate, "Advocates Zoom In On... *Advocacy & Abuse Prevention*", December 2020 Zoom discussion

"I believe DSS [Department of Social Services] lacks insight into the significant complexity of cases we work on - the vicarious trauma. Often, I feel their focus is on insignificant data - that an issue presents, but from that, several others result - yet only one of those issues will count in the data. They don't count the other work we do in their numbers, yet will say well you have a choice as to whether you address those other issues. We can't just leave someone in limbo saying come back to us in 3 or 6 months when we have addressed this first issue, because that other issue won't count in our stats. This is not okay."

VIC Advocate¹³³

"I think we only see the tip of the iceberg in advocacy. We wouldn't see that many at all, compared to what's going on out there."

NSW Advocate, March 2021 Zoom workshop with DRC

"...organisations need to allow advocacy, sw [support workers] are too scared to reach out to us from group homes. They're terrified they will lose their jobs".

VIC Advocate, April 2021 Solutions focused workshop with DRC

A legislative basis for independent advocacy services to enter institutional, residential and service settings would allow for isolated consumers to be educated about their rights, be assisted to report incidents of abuse or neglect, and make complaints.

As discussed above in [Section 5](#), Self Advocacy training assists people with disability to identify and report inappropriate behaviour and abuse. The Senate Community Affairs References Committee highlighted the importance of "access to facilities for advocates" and independent Self Advocacy programs.¹³⁴

¹³³ VIC Advocate, "Advocates Zoom In On... *Advocacy & Abuse Prevention*", December 2020 Zoom discussion

¹³⁴ The Senate Community Affairs References Committee (2015) *Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability*, Final Report, p196.

Section 9: Safeguarding rights and wellbeing of people with disability¹³⁵

Themes that emerged strongly in our engagement with advocates were:

- ensuring the independent advocacy sector is resourced, networked and supported to meet the needs of people with disability;
- refocusing on rights across all service settings; and
- investing in rights awareness and education across the community.

In addition to the formal safeguarding frameworks, these are all important components of safeguarding the rights of people with disability to live free from violence, abuse, neglect and exploitation. Achieving meaningful outcomes in these areas requires dedicated funding.

Ensuring independent advocacy sector can meet needs of people with disability

At the COVID-19 hearing in August 2020, Every Australian Counts Campaign Director Kirsten Deane noted:

“...we need more funding for advocacy, both systemic and individual advocacy. During the pandemic I had cause to speak to a number of advocacy organisations, either to refer people for help or to share information and resources. And I am aware that many advocacy organisations have closed books and some of them have even closed their waiting list. I think in the middle of a global pandemic, when people urgently need help, that isn’t acceptable. We also need funding for systemic advocacy because it is those organisations that are working with government to make sure that government responds appropriately, and that people aren’t left behind.”

DANA has previously argued that advocacy should be funded proportionally to disability service delivery expenditure and through a model that values independence and accessibility. However, no equivalent increase in funding has eventuated. Despite the last decade bringing huge commitments and investments in disability supports, the security of funding for independent advocacy has decreased, with funding contracts and agreements often nearing expiry before renewed funding is announced or confirmed, and advocacy organisations in several states fearing State level funding might cease altogether and needing to collectively campaign for continued resourcing of the vital work they do.¹³⁶

¹³⁵ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) Issues paper - Safeguards and quality, p6. Question 1 asked: “Question 1: What are the best ways to safeguard people with disability who may be at risk of violence, abuse, neglect and exploitation both when they use services and in other areas of their lives?”

¹³⁶ e.g. in NSW: [Stand By Me](#) 2018 Campaign, and in QLD: [Stand with us](#) campaign 2021.

“Advocates are an excellent safeguard ...obviously, especially a rights-based safeguard, and given that we've always struggled to keep funding or get enough funding, there's just not enough advocacy because advocates are also involved in general awareness raising about people's human rights. We're not just standing alongside people and advocating for them, we're doing a lot of that filling in the gaps, trying to make sure that there are clear pathways for people so that they can get their needs met as well as raising awareness.”

TAS Advocate, November 2020 Zoom workshop with DRC

“We are often having to triage and choose in terms of which person gets our support and we must look at, will they have a legal practitioner supporting them at court etc.

We are small agencies, and we must make a call on who gets our support at any given time, so funding for advocacy will be important. It would increase the ability to provide support to more people.”

VIC Advocate¹³⁷

“There needs to be more specialists within Advocacy organisations that are experienced in CP [child protection] law... in addition to development of a national training package targeting this specialized knowledge and skill area.”

QLD Advocate¹³⁸

“In working with individual issues, an advocate is often the first point of discussion around any violence, abuse, neglect and exploitation. We usually connect persons to appropriate supports, are these supports - i.e. inclusive and supportive of disability (not often, as workers in family violence, children services, housing), often feel that disability is not their "specialty" and often refer back to advocacy.”

VIC Advocate¹³⁹

“One to one support - advocates need the skill to see the bigger picture. e.g. clients may come in for one issue, however there are layers to uncover, like an onion peeling each layer at a time and advocating on violence, abuse, neglect,”

WA Advocate¹⁴⁰

¹³⁷ VIC Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

¹³⁸ DANA's 2020 Child Protection Systems survey, Response from QLD Advocate

¹³⁹ DANA's 2020 Advocacy and Abuse Prevention survey, Response from VIC Advocate

¹⁴⁰ DANA's 2020 Advocacy and Abuse Prevention survey, Response from WA Advocate

“Advocacy organisations should be supported by all levels of government by public declaration of their role as preventative measures for vulnerable people with disability, and their role in building capacity in people with disability to enhance autonomy and empowerment, and promoting people with disability as equal citizens who contribute greatly to humanity and community.”

QLD Advocate ¹⁴¹

“I have worked with a number of people in the justice setting, but they are all people that are already known to [WA advocacy organisation], or their family are known to us, and this is an issue that I think the advocacy organisations have been running up against a lot, particularly in the last couple of years, that the people who come to our services are already people who know us.

So, because of often our long wait lists and our long... our capacity is directed towards helping individuals, we're not able to get out and do as much outreach as we would like to. So the people who may need support, if they don't know that support exists, they can't access it. So, as an organisation, and I imagine as a sector, we would like to see more people being made aware that these services exist, and then us being actually available to assist them without huge wait lists, if that makes sense.”

WA Advocate, October 2020 Zoom workshop with DRC

Advocacy programs need more funding to deliver more advocacy, but their organisations are in dire need of capacity building and opportunities to hold advocacy conferences state-wide and nationally for professional development, increased learning and sharing of ideas ... Governments should promote all the advocacy targets [health, justice, employment, etc] as opportunities for continuous improvement and that working with advocates is a desirable and productive measure.”

QLD Advocate ¹⁴²

Advocates play “a huge role [in safeguarding], but sadly a limited role due to funding constraints. When you look at funded advocacy organisations’ area of coverage, and the amount of workers per population, you see a very stark picture of support able to be provided. This issue also promotes a lack of engagement with appropriate inquiries, royal commissions etc... as time is so poor”

VIC Advocate ¹⁴³

¹⁴¹ DANA's 2020 *Advocacy and Abuse Prevention* survey, Response from QLD Advocate

¹⁴² DANA's 2020 *Advocacy and Abuse Prevention* survey, Response from QLD Advocate

¹⁴³ DANA's 2020 *Safeguarding rights and wellbeing* survey - Response from VIC Advocate

"I've dealt with two really, really egregious abuse cases in the last two years. Both of those cases took between 18 months and 12 months to resolve. And in neither case was the referral because anyone suspected abuse. In both cases, the referral was for something really almost insignificant, where referring for advocacy was a tick box issue. Neither of the people had any formal communication, and it was about doing quality intake screening and identifying fundamental unmet needs, and about not accepting the referrer's formulation of advocacy needs. And in both those cases, it also required having to go to the guardianship tribunal to secure the right of that person to advocacy and consent and things like that.

That's a massive, massive amount of resources, and time, and expertise. And it's quite an intimidating situation to be put in, as an advocate, when you are brick-walled and the shutters are being pulled down. If those two cases are even remotely representative of what I suspect is out there, the sector would collapse under vicarious trauma. We don't have what we need to be able to do it. There are not the resources in terms of supervision to be able to deal with this level of work."

NSW Advocate¹⁴⁴

"Our funding has just been cut in certain areas, so we have a waitlist now for different sections of where we can provide support."

WA Advocate, November 2020 Zoom workshop with DRC

"...we've seen a trend over the last say three years of doubling each year...doubling of demand, which will... so this year we will have a waitlist. We have always strived not to have that, but the demand has been really great. So we will start to have waitlists. We will also start to have sort of a checklist of whether or not there are other services who are more appropriate for the person to try to get assistance from. So if they have a psychosocial disability, we might refer them to [mental health organisation] as their advocate as opposed to us, unless they've had a difficulty there, and then we'll keep them. But yeah, there's been a huge demand.

One of the things that we've seen really change about the demand is there are a lot of our referrals, like maybe as much as 50%, that come from other agencies ... We get referrals not necessarily from the clients themselves, but from the services they access.

Then what we do is exactly what was said and that is we try to build their capacity, we try to offer them support and then try to find the best way to navigate the problem that they see they have, so making it very person centred. We often identify that there are lots of things we

¹⁴⁴ NSW Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

would like to help them with, but they themselves don't identify that as the problem. So that's where we stop."

NT Advocate, November 2020 Zoom workshop with DRC

"Waitlists are problematic. This new environment is causing backlog including a waitlist for advocacy."

VIC Advocate, February 2021 Zoom workshop with DRC

"...I think one of the benefits of advocacy being an independent service for people with disability is that the power of advocacy is the independence and... attaching rights to a person. We can't be part of a safeguarding system, you know, we don't want to be attached to government. It's different to lawyers who are bound by legislation and the limitations of their role, but I think the power of independent advocacy is that we can be incredibly agile and put ourselves in all sorts of corners where essentially nobody else can get to, and if we have kind of more strength to be able to get into some of those places, then we can be part of the safeguarding landscape more effectively."

VIC Advocate, April 2021 Solutions focused workshop with DRC

"Most advocacy in Victoria is inaccessible because we're all at capacity."

VIC Advocate, April 2021 Solutions focused workshop with DRC

Refocusing on rights in service settings

In addition to the variety of roles that advocates play in relation to building the rights awareness and capabilities of people with disability (discussed above in [Section 5](#)), advocates often build the awareness and capabilities of staff in service settings, whether through delivering training, or through informally raising awareness and "reframing issues and behaviour" in the course of their advocacy work.

In seeking positive outcomes for people with disability, advocates will often deliberately avoid being overly combative or adversarial in order to quietly and diplomatically educate and negotiate with the personnel in relevant service systems to shift their perspectives and approaches. Advocates promote greater focus on human rights in service settings, including building [recognition of 'behaviour' as communication](#) (as discussed in Section 4 above):

"...one of the things that we find is that one of the biggest roles that we play in advocacy is about reframing issues and reframing behaviours. So I guess, because we work exclusively with people with intellectual disability, one of the things that we see is that a behaviour is interpreted in a particular way and people respond to it with restriction or in a punitive manner."

And one of the things that we constantly do is reframing issues in a kind of rights sense. So a lot of the time we're not actually busting in and making complaints and doing things, but actually we're kind of very subtly doing a whole lot of education around rights.

And that's one of the huge absences in the community at large, is that the kind of knowledge of people's rights and inclusion, and also the diversity of people with disability is... people with disability are still very much excluded, discriminated against and marginalised. And so, if you have a sector that is very new, and with a lot of new people in it, often those people come in with a whole lot of kind of community attitudes about how people with disability should be treated, and especially people with cognitive disability, and the risks that they pose and the risks they pose to themselves and the decisions they're not able to make, all that kind of thing.

So a lot of the prevention work we do is kind of going in, talking about how you might sort of see an issue differently, and reframing people's understandings of things, which I think is... like that's a huge thing for us and it's an educative function, but it's also a preventive thing because what we find is that people then come back to us again and again and say, "Oh, so I've got another client and I was remembering that time you told me" blah and so you can provide them with a whole lot of resources or education around how you can do things and see things differently in a more rights-based way."

VIC Advocate, April 2021 Solutions focused workshop with DRC

The extent to which advocates can engage in building the capacity of disability services to "reframe behaviours" and other issues, is naturally dependent on the willingness of staff and systems to be open to this engagement and supportive of cultural change, and is frequently limited by current funding and capacity constraints.

Investing in rights awareness and education across community

There is lack of education and awareness among many people with disability of their human rights and legal rights, as discussed above in Section 2: [Lack of rights awareness](#).

There is also inadequate focus on rights in service settings, including in relation to decision making, restriction and community participation and inclusion (See [Section 12](#)).

"I think that the nature of restrictive practices is that either there's an ignorance of rights, so the staff are not aware of what they're doing, or maybe they're ignoring someone's rights, and so that person is isolated... And so, if there's not really a great knowledge about people's rights, they're not really going to know about advocacy either or about when to refer to advocacy. So it's sort of like a double isolation chamber."

TAS Advocate, November 2020 Zoom workshop with DRC

"...it's really fundamental that people have education and understanding about these issues so that they can differentiate and they can understand what is abusive behaviour and what is acceptable legal behaviour. And that education also extends to all people, including people with disabilities, so that they know: 'Look, this is not right. I shouldn't be treated like this, and I really deserve better.' So education and information on this is fundamental on all levels, and putting in place systems of policies and processes that safeguard against this. This kind of behaviour happening is also pretty important I think."

ACT Advocate, October 2020 Zoom workshop with DRC

As suggested in Section 4: [Human rights training](#), training for staff in human rights principles and what constitutes abuse needs to be strengthened in the disability sector. However, education and awareness raising about rights also needs to extend across different service systems and throughout the wider population to be truly effective.

"Not just the person with a disability ...teach people about their rights and basic rights as a human being... but the people they are working with, they are the ones who need to know... You are working with a person with particular needs and particular challenges and particular concerns, so you have to think outside the square for a while and put yourself in their shoes for a while. Some workers think they know everything, but unless you work with a person with a disability, unless you walk in their shoes, you don't know anything."

I can speak on that from a personal point of view, some of you may know, because I am blind. I can take that experience. Speaking from that point of view. And I certainly get treated differently. Unless I stand up and tell them my rights."

NSW Self Advocate¹⁴⁵

Effective outreach activities into congregate or closed settings are needed. Advocacy organisations often engage in this education and capacity building work, but this is often limited by overstretched capacity and funding constraints, and/or by gatekeeping and lack of access into those settings.

During the Australian Law Reform Commission Inquiry into Equality, Capacity and Disability in Commonwealth Laws (completed in 2014), a number of stakeholders advocated that the envisaged oversight and complaint handling body for the NDIS (i.e. the Quality and Safeguards Commission) would also have responsibility for promoting access to advocacy and supported decision-making.¹⁴⁶

¹⁴⁵ NSW Self Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

¹⁴⁶ Australian Law Reform Commission (2014) *Equality, Capacity and Disability in Commonwealth Laws* (ALRC Report 124) p154.

Under the NDIS Act, the Quality and Safeguards Commissioner “*must acknowledge, recognise and respect the role of advocates (including independent advocates) in representing the interests of people with disability.*” According to discussions with advocates, the NDIS Quality and Safeguards Commission has not yet played a significant role in ensuring the visibility and accessibility of independent advocacy to all NDIS participants.

Section 10: People who need additional support¹⁴⁷

“If effective and high-quality advocacy, it can be crucial in ensuring the safety and well being of the person concerned. This is particularly the case if the person has no involved family or significant others.”

VIC Advocate¹⁴⁸

As discussed in Sections 8 and 9 above, people with high support needs; people who face communication barriers; and people who do not have much or any informal supports are often the people with disability supported and prioritised by advocacy organisations in managing their resources. They are also often the groups of people that advocates fear do not have the means of accessing support from an independent advocate, as this may be needed to even initiate a complaint or report abuse, violence, neglect or exploitation. Advocates often voice this fear that they “*are only seeing the tip of the iceberg*” and are not able to reach those people who need support to speak up.

There is also uncertainty about whether current systems are adept at identifying who needs additional support. For instance, there is little clarity about the internal processes of the NDIA in flagging which participants (or applicants) may need additional support, and whether and how they are referred to independent advocacy organisations or to other relevant safeguards.

“In our organisation, we deal a lot with people in supported accommodation who do not have any relatives and what I have found, and what other advocates have found in our organisation, is that these people are extremely vulnerable. They often have no choice in the care that they have. They often have no overseeing person to look after them and, in fact, one person got moved from one house to short term accommodation, and the only reason they knew about it was because the person who was running the house rang me and said that they needed an individual advocate for this person, as she didn't want to move. And I think it's really important that people who are in supported living accommodation who do not have any relatives are allocated an advocate that has no vested interest either in

¹⁴⁷ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p6. Question 7 asked: “*What safeguards are required for people who may need additional support, such as people who do not have informal supports like families or other advocates, people who face communication barriers, and people with high support needs?*”

¹⁴⁸ DANA's 2015 *Quality and Safeguards survey* - Response from VIC Advocate

accommodation or service provision, to look after their needs, because it's quite obvious to us from our experience that they are often left very vulnerable" ...

"Anyone who is in supported living accommodation that does not have family members should be allocated an independent advocate."

NSW Advocate, March 2021 Zoom workshop with DRC

"Having access to an independent advocate greatly reduces the segregation someone experiences living in supported accommodation, and if there was a greater ability for every person with disability living in supported accommodation to have access to an independent advocate, I think we would see a huge reduction in the amount of segregation because, for myself, if I am advocating for someone who lives in a group home with four other people, I will ensure that that person, once I have dealt with the critical issue that I've come on board to advocate for, I will then look at everything else that's happening for them and ensure that they are accessing the community, that they are engaging in activities of their choice, in enriching... I will advocate for them to ensure that that is all set up before I will, I guess, view my job as done. And the problem is that there are so many people living in supported accommodation that don't have anyone to refer them to an advocate, that don't have an awareness of it, or access to it. And if they did, it would improve the quality of their life, in my opinion."

"...there needs to be a cultural change in the way advocates are viewed in a lot of settings, that the input from an advocate isn't to create trouble or to make someone's workplace more difficult, but the actual reason that we're there and engaging in the work we are engaging in. So a bit of education for the sector, as well as having people assigned an advocate. If someone's got a public guardian assigned to them and no one else in their life, no level of informal supports, or if they don't have a guardian, I think it's absolutely a requirement that they should have an advocate appointed."

NSW Advocate, March 2021 Zoom workshop with DRC

"...if you have someone who has a significant disability or who has communication needs, then they actually rely on their support or someone to actually contact an advocate. And that's the assumption, that they actually know what abuse is, because I had one just a couple of days ago who was thrown in the shower with her... by her support workers fully clothed. She thought they were just having a bit of mischief. So there's real... [problems with] understanding around what abuse is. But, also, there's a dependence on support workers to actually contact an advocate - that doesn't always happen."

TAS Advocate, April 2021 Solutions focused workshop with DRC

“it's hard to say something was prevented when it didn't happen, because you're saying some intervention stopped something happening and then you're saying it didn't happen because of that. ... If you've got a person coming in with fresh eyes who's not paid by that provider... and we're talking SIL [Supported Independent Living] settings and the NDIS world of clients and providers here... so if you've got someone coming in who's not a community visitor, but an independent advocate who can ask questions and say, "How has your day been? What's going on?" the value of advocacy in these situations is so much more valuable where people are very vulnerable because they've got communication problems and they don't have family and friends around them. So an advocate makes that person more visible. Suddenly the staff are aware 'this person has a right to come in, ask questions, talk to us and we are being watched'.

So the example I've got is the house that I mentioned earlier..., someone, a support worker, had been buying groceries and those groceries had been disappearing and the advocate noticed why [there] was this big pork roast in the freezer and it's gone and I know it wasn't cooked up and used for the protégé, for the person with disability, she never got to eat any of it.

There were a few other questions about groceries being bought, using the funds of the person with a disability and being ticked off without anyone, a family member or an advocate, seeing it. I inquired on behalf of the advocate and wrote an email and suddenly things started to happen and they launched an inquiry and that particular support worker was no longer working at that location.

Now, she'd been getting away with it and who knows, it may be just a bit of pilfering, which is not just pilfering, it's a breach of trust and an example of the financial abuse, it could have gone further. She had no one watching.

This is the sort of thing that advocates can do, they can nip it in the bud. And you can't say random things that didn't happen here because you... they were going to happen definitely, but you can see the way it was going.”

QLD Advocate, April 2021 Solutions focused workshop with DRC

Like other models of independent advocacy described above in [Section 5](#), Citizen Advocacy organisations are inadequately and inconsistently funded throughout Australia, with Citizen Advocacy programs completely absent from the ACT and NT jurisdictions and many regions around Australia. The volunteer model of Citizen Advocacy has great potential to initiate and guide long term supportive relationships for isolated people with disability.

“...Citizen Advocacy... would be very good and my understanding is that, you know, apparently it's based on Wolfensberger's theory that the person's not just a volunteer, but they kind of stay there throughout their life ... the way it is now, advocacy has a limited...

once you... finish the issue, then you kind of close the case. So I think there would be a lot of added benefit to having Citizen Advocacy in the lives of very vulnerable people.”

ACT Advocate, October 2020 Zoom workshop with DRC

“All people with disability who do not have informal supports need someone on their side. Citizen Advocacy can fulfil this role. Currently, advocacy organisations are not well funded or resourced and are not available in enough capacity in enough locations.

Where there is individual advocacy for persons with disability who experience abuse, neglect, exploitation and discrimination, it is almost always at full capacity.”

QLD Advocate¹⁴⁹

Other forms of capacity building that are especially relevant to an individual who lacks informal networks and/or who needs additional support include:

- **Circles of support** – a group of people who volunteer to meet with a participant on a regular and ongoing basis to help with the thinking, planning and implementation of their personal goals.
- **Microboards** – a small group of people, typically committed family and friends of a person who experiences challenges in life. That group of people form an incorporated association for the benefit of that person. Depending on a person’s particular needs, a Microboard’s role can include assisting with coordinating support services, finding and keeping employment, facilitating friendships and social community.
- **Social role valorisation activities** – ensuring the individual assumes a valued social role in their community.¹⁵⁰ This sometimes occurs through customised employment, setting up a microbusiness, inclusive volunteering programs or other formats.

(See discussion above in Section 5: [Other forms education and capacity building](#) subsection.)

Such activities build intentional relationships and provide support for decision making by listening to the person’s ideas, supporting their choices, identifying their goals and aspirations and planning to make things happen.

“If NDIS supported people to develop circles of support, or if this could be offered with paid facilitation, this would naturally bring more people to someone’s life.

¹⁴⁹ DANA’s 2020 *Advocacy and Abuse Prevention* survey, Response from QLD Advocate

¹⁵⁰ Social role valorization (SRV) is a relationship theory of empirical knowledge for the design and rendering of formal and informal services and relationships to people with any need or condition, especially those who are devalued or are at risk. This theory often informs the activities, training and projects of Citizen Advocacy organisations and also some family advocacy organisations. E.g. [Roles-Based Recruitment | A Resource About Support \(imaginemore.org.au\)](#)

Anytime I have tried to raise circles of support, and funding attached to this, NDIA planner was clear in denying this”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“...long term, we need to make sure that people who are at risk, you know, that we are funding circles of support, so we're funding supported decision making, that we are building into the supports they're getting, these safeguards that they need to protect them in the long term and build up that safety around them, and it's something that I know the NDIS is talking about, but if and when it becomes a reality, we don't know.”

WA Advocate, October 2020 Zoom workshop with DRC

Section 11: Meeting diverse needs¹⁵¹

In the course of discussions, advocates spoke about how the needs of First Nations people, culturally and linguistically diverse people, and children and young people with disability need to be more fully addressed in existing systems and supports, including in the provision of independent advocacy.¹⁵²

First Nations people with disability

“... every Aboriginal community is not the same. We are very different, we are very diverse, we have different needs and different resources. We have different aspirations and different interests as well.

We cannot do a blanket cover for everybody, you know? Everyone has to be looked at individually throughout Australia. You have got traditional people, you have got urban people, who all have different needs. Some are isolated, socially isolated as well as geographically isolated. One solution does not cover all.”

NSW Advocate¹⁵³

¹⁵¹ Royal Commission into Violence against, and Abuse, Neglect and Exploitation of People with Disability (2020) *Issues paper - Safeguards and quality*, p7. Question 10 asked: “How can safeguards and complaints processes be improved to better meet the needs of First Nations people, women, culturally and linguistically diverse people, LGBTIQ+ people, and/or children and young people with disability?”

¹⁵² For insights on how restrictive practices affect these groups, see: [Reliance on restrictive practices to control behaviour](#) in Section 12 below.

¹⁵³ NSW Self Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

“We identified in one of our rural/regional areas, it was not being covered and there was a lot of people missing out on NDIS access. They were a lot of First Nations communities. We were able to get funding for one year for supporting NDIS access, but the barriers were still there, and that took a lot of building those relationships.

Some of those areas still weren’t covered and there is a massive concern out there that in remote and rural areas where a lot of communities are, that the supports are not there, as well. They have to come from out and into these areas. It takes a long time and a lot of the areas are not covered. [Those are] the barriers I feel that we face, and I believe that First Nations people have a massive mistrust as well. It's how we get over those barriers.”

QLD Advocate¹⁵⁴

[For people living on country and in their communities, the notion of segregation is] “totally alien to people. Everybody lives with their family. Your identity comes from your family, who you're related to out in the community. It's like a big web of support in terms of everybody being related to everybody else and people know what's expected of them in community because of that web.”

NT Advocate, November 2020 Zoom workshop with DRC

“Certainly our clients definitely feel that they are part of their community. I mean, they're certainly First Nations clients who are [integral] parts of their families, so for the most part they don't actually even see their disability necessarily as a disability, yeah. The people that we seem to see are actually quite an [integral] part of our society.”

NT Advocate, November 2020 Zoom workshop with DRC

“Advocacy is critical for people with disability in remote indigenous communities. Most people with disability in our region have English as a second or third language and literacy levels are very low. It would be almost impossible for people with disability to manage all the requirements of Government without advocacy support. The move away from having staff in offices that people can visit to get information and have problems resolved and toward having all systems eg. My Aged Care, NDIS, My Gov etc. online... assumes that everyone has English literacy and computer literacy. There are cohorts of people in community who cannot navigate these systems and will consistently require advocacy.”

NT Advocate, April 2021 Solutions focused workshop with DRC

¹⁵⁴ QLD Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

In discussions, advocates from Aboriginal communities emphasised the importance of building relationships with First Nations organisations, networks and individuals:

“When you meet someone that has an issue... Maybe they have ten other things in their life but they won't speak up. But you'll only learn about that when you form a relationship, and you go into that home. When you do that, you will find other people in that home that need support as well...”

NSW Advocate¹⁵⁵

“Everything is rooted in the loss of identity, culture, removal of their lands, the trauma across generations. And a lack of understanding of presentation of trauma ... As an advocate, I would like to be better equipped and be able to be linked with the First Nations services and have training... That's a starting point for me, that there needs to be work done right across every sector of society for our First Nations people. Yes, there has been some improvement, but a lot is minimal. I think there is a fuss made that the government has done this or that, but it is minimal compared to what needs to be done, the investment that needs to be made.”

VIC Advocate¹⁵⁶

“I think we need to be talking to the people that we are advocating for more... In the aboriginal community we say nothing about us without us. That needs to be done. We can't advocate unless we have the grassroots people there. A common-sense response, I think.

There needs to be a lot more done with Aboriginal people, in particular. I know a lot has been done, but the problems are still there, so we need to do more.

...I think people with ID [intellectual disability], for example and physical disabilities, who come in contact with the legal system, police... Police would be the most uneducated people I have ever seen when it comes to working with people with disabilities. And with intellectual disabilities. And that is only from my point of view. I'm sure others have it, but police and educators, the education system in a lot of areas, they need to understand a bit more about the people they are working with and understand the disability as well.”

NSW Advocate¹⁵⁷

¹⁵⁵ NSW Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

¹⁵⁶ VIC Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

¹⁵⁷ NSW Self Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

"I have been working at my role as a disability advocate for just over one year. The clients have jumped 100% or more, who have attended the service. Most of my contacts are out of work. I am a local community person and most of the people in this town are my family.

They know me personally and they know what I stand for. I just feel like you need a local person in that area. ... you need to consider the grassroots people who have connection to that area."

WA Advocate¹⁵⁸

"...lots of those people do have NDIS plans now, especially on the APY Lands [Anangu Pitjantjatjara Yankunytjatjara], and yes, there's sometimes, not always, funding in those plans for positive behaviour support plans, but it becomes extremely complex because of it being cross cultural. What is acceptable if someone is in a residential service in town in terms of managing behaviour may not be so out in community. People don't want to behave, families don't want to behave differently to other families. So it's very, very difficult for families to put in place behaviour management strategies if those strategies are not culturally appropriate and culturally acceptable.

So often, there's a really good plan and it works well when the client is in town getting respite, but when they're home again, the family don't implement that plan because it's not culturally appropriate. It's not manageable for them, it's not the way that they would normally interact. So it kind of - unless you've got consistency - those behaviour plans are very difficult to implement and to get that really good outcome of the participant understanding what the expectation is."

NT Advocate, November 2020 Zoom workshop with DRC

"...we have assisted a number of people who were in prison that we were able to keep in one place, get an NDIS plan, transition them out. It's been difficult to keep them, or to assist them, to stay on a plan. No matter how much pre-planning we do when a person is in prison or in juvenile detention, when they get out there's a lot of competing cultural stuff that goes on. Sometimes, they'll have a family and so they don't manage their money very well - just a variety of things, just trying to locate them to meet their appointments or for their community engagement person that's being supported through the NDIS to even be able to find them sometimes is hard. ... We've had a number of people that we've assisted to get phones and to do that. But when a person's priority is food, accommodation, family responsibilities, you know, that other stuff doesn't really work into their lives."

NT Advocate, November 2020 Zoom workshop with DRC

¹⁵⁸ WA Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

“There have been a number of providers who've become quite flexible in the way they deal with people with psychosocial disabilities, providing them a variety of different kinds of ways of having accommodation, that sort of thing, the community access people being quite receptive to changing wellness of a person and being flexible with that.

I would say that we as an [organisation] agree in that what you need to be is you need to be culturally appropriate and aware and provide those quality services. I also think there needs to be some sort of quality and safeguards around some of that flexibility, only to monitor what actually takes place. We ... have asked for the community visitor program to be brought back for people with disability as a way of monitoring some of those things. But other than that, you know, we are happy with the way people generally are being flexible around the way they do things.”

NT Advocate, November 2020 Zoom workshop with DRC

“The only other things that I have thoughts on are, or feedback from, is in the prison system, people with disabilities-, and they've told me that they have been given a particular medication and it's a medication that's one fits all people, not the appropriate medication, and also in terms of with the guardianship orders -- people with disability who have been put under guardianship orders and who have had contact with DOCS [Department of Community Services]¹⁵⁹ - not feeling that they've been able to have their say in what they're hoping for in terms of restoration or access to their children.”

NSW Advocate, March 2021 Zoom workshop with DRC

See Appendix A for more comments and ideas for [Meeting the needs of First Nations people with disability](#).

[Culturally and linguistically diverse people with disability](#)

“We are linking in with the local multicultural service and wanting and requesting that we can do some sessions, information sessions, with their paid staff and their large volunteer contingent to share about our service in terms of its advocacy, general issues, NDIS and also the Disability Royal Commission.

We are really aware of our lack of reach into other communities. We have made some gains in the local Sudanese community, but COVID-19 made that enormously difficult to maintain supports in in terms of accessing interpreters in a timely way. Because we are very aware that different community groups have different ways of working, it will often be a drop-in

¹⁵⁹ Now Department of Communities and Justice: [Communities and Justice \(nsw.gov.au\)](https://www.nsw.gov.au)

session rather than a set appointment - we tried that, and it did not work - so it was a bit more responsive, but also extremely difficult off the back of that to get an appropriate interpreter who spoke that specific regional language.

When hearing was an issue as well, we obviously could not use a telephone interpreter because those are the ones that are the quickest to get. So those are some of the complexities of it, and why we are looking at trying to engage with this multicultural service, which does have that reach, and we'll hopefully be doing some shared training and upskilling of our staff to become more responsive and aware of how we can meet people's needs."

VIC Advocate¹⁶⁰

"...for example, letting people know about Official Visitors and putting posters in different places has been one way, but I specialise in advocating for people from multicultural backgrounds, and I tell you that they don't read that, and the best kind of communication is someone that a person knows who is able to communicate in a way that that particular person can understand - might not even be verbally, there are different ways to communicate, so there has been some work, but we need to move away from just posters on the wall."

ACT Advocate, October 2020 Zoom workshop

"I feel very strongly, and I guess working in the disability sector for many years, that clear message is that... I mean, I will never be an expert in understanding all the cultures that exist, because within each cultural group there are more groups.

As a response, at the very least, I think a quarter of any of our work is making no assumptions and actually learning from the expert, using the person in front of us that we are providing a service for, and being prepared to be challenged in our views, and being open to deeply listening to whatever it is that they are seeking from us, from me as a worker, and how do I respond to that.

I think it is important to remind ourselves... that it is OK to make mistakes. It is about acknowledging that and checking in with that person if you are not sure. They are the expert, so we're learning from them."

VIC Advocate¹⁶¹

"Particularly for newly arrived migrants - they do not have the best experience with services, with formal supports and sometimes they do not know that the support exists. So that's just

¹⁶⁰ VIC Advocate, "Advocates Zoom In On... Advocacy for people from culturally and linguistically diverse communities", November 2020 Zoom discussion

¹⁶¹ VIC Advocate, "Advocates Zoom In On... Advocacy for people from culturally and linguistically diverse communities", November 2020 Zoom discussion

to clarify that understanding some of those cultural values behind why a person does not want to access supports and services needs to be at the centre of how to design and adapt them to CALD [culturally and linguistically diverse] voices.

The second point I wanted to add is...around parents and families, discussion of access and supports need to be shared amongst multiple decision makers within the family unit. Even though the person with disability is the one advocates will mostly be working with, the conversations with supporters and how to involve supporters in a way that benefits and contributes to... supported decision making of the person, is really important.

There is a very fine line to be drawn around supporting someone with CALD [culturally and linguistically diverse] background to participate and supporting the supporters, as you want to maintain the capability of the person with disability to participate in the process.

So, that fine line is... a lot of training. It is worth noting that at the high level, the decision-making within the family unit does very much carry forward to affect how well someone can engage with these services.”

NSW Advocate¹⁶²

“You really have to support and empower your client through the issue that they come to you with. I think for me it is really important for us to be aware, because even though ...yes it is problematic, putting everyone in one basket, I guess... I think cultural training and understanding cultural sensitivity are so important for this kind of work.... I think we have to be really aware and careful, I guess, when we are working with clients not to make assumptions based on various regions that they come from.

Also, clients who are presenting certain issues, whether it is refugees on uncertain visas, what have you, rather than coming from a more knowledgeable and education background where [we] tend to assume that we know what they mean, we actually open ourselves to possibilities of just listening to the client and working closely with the families in order to actively listen and allow them to inform us in what options we can provide them and empower them in that decision-making process.

It is quite challenging, it is not easy all the time ...Just with these communities, I am sensing that there is a lack of resources and even communication with support workers and NDIS, it is so complex. If I'm feeling overwhelmed with my experience and background, I cannot imagine what my clients who have a disability, or major issues, or barriers... you just have to

¹⁶² NSW Advocate, "Advocates Zoom In On... Advocacy for people from culturally and linguistically diverse communities", November 2020 Zoom discussion

be really mindful of what options can we present... how we can advocate for better resources, cross-cultural training and face-to-face, as well..."

VIC Advocate¹⁶³

Children and young people with disability

"[Restrictive practices have] the same effects they'd have on any of us if we had to deal with that, but of course people with disability who have heightened vulnerability, and particularly if they have communication difficulties or have difficulties expressing how they're feeling, or even worse, it would be tantamount to torture.

We're almost in the final stages of our submission on this Royal Commission and I guess my concern, biggest concern, is that we start doing this to children while they're in school and at home and if this continues, their life is mapped out for them in ever-increasing levels of severity and harshness, and more than likely to end up in indefinite detention somewhere with multiple layers of restriction. So there's nothing to prove that applying restrictive practices on anyone does anything to help them."

QLD Advocate, December 2020 Zoom workshop with DRC

"With a lot of my advocacy experience, I'm talking to parents, so we're talking about children who are experiencing these restrictive practices of a variety of ages, but it's not necessarily... I don't think it's classified separately as restrictive practices; it's just what they have to deal with and the restraints or the restrictions that they exist with. How that translates to an education setting, from my experience, I'm not hearing that the student is involved in talking specifically about restrictive practices."

NSW Advocate, March 2021 Zoom workshop with DRC

The lack of effective supports, and/or lack of clarity and education about restrictive practices for families, parents and carers of children or young people with disability also contributes to confusion and reliance on these practices in private homes:

"...in the few cases that we've come across at [NSW advocacy organisation], I personally have realised that it's quite hard for families ... I work with individuals, and predominantly in the NDIS space, so in a lot of the cases, families find it hard to differentiate what is behavioural support and where does that cross the line to restrictive practices. And then to also answer your question about is it authorised or not, without that really clear understanding from the families, the carers' perspective, well, there's a very high chance that lots of families out there

¹⁶³ VIC Advocate, "Advocates Zoom In On... Advocacy for people from culturally and linguistically diverse communities", November 2020 Zoom discussion

are undertaking restrictive practices without knowing that it's actually restrictive practice, and then for them to be told after the fact, there's just a lot of confusion around how it's meant to work and who's responsible for what and whose responsibility is it then to work out who does the paperwork, who do I see first, who do I talk to first, and it's all just like a ball of mess in their mind, and carers become so overwhelmed with this idea of restrictive practice and all the finer details around the different environments that they're in and how that changes and what their role is, what they can and can't do, how that then varies from when their child turns 18. From my experiences, that's just been a really confusing situation and often enough it just flies under the radar.”

NSW Advocate, March 2021 Zoom workshop with DRC

“I think that when it comes to restrictive practices, the behaviour management consultant, or whatever the correct terminology is, would have more input into a restrictive practice than even the person with disability or the family members, and I think often families and carers, but particularly families or people close to them, are left out of a lot of this and, in some ways, they're the informal advocate in many cases and when they are shut out of process, then that's already a problem. So I think perhaps one way forward is to say when there are behaviour management plans put in place with restrictive practices, then people are at least informed about advocacy options around those things.

Just in terms of success stories, one of the things I find very interesting is that when I'm talking to a parent who has a child who has been subject to restrictive practices, authorised or unauthorised, that in a number of cases, it's not consistent every school year - that somebody might have better experiences in one school year than another school year or in one education setting than another education setting. So I think that's potentially part of what needs to be explored in terms of what works and what doesn't. But usually it's not about the quality of the authorisation or of the behaviour management plan, but it's about the approach of that school or that teacher or the communication between an educator or a system and a family who knows the person.”

NSW Advocate, March 2021 Zoom workshop with DRC

“...we hear from a lot of families. Over the last five years, our calls have doubled in relevance to education and specifically the lack of adjustments being made to account for a child's disability, and often it's that lack of adjustment that causes a reaction from a child, which they now call - they like to label it a behaviour of concern - and then all the onus and blame becomes the child's problem, rather than looking at the environment around the child, the conditions around the child and what are the needs of that child if we're sort of looking at the order of need, the hierarchy of needs, what are those needs? Are we meeting them? What adjustments can we make to really support this child to feel safe, to have a safe person to go to when they don't feel safe, to have a safe place to go to when they don't feel safe? So that

even if they are nonverbal, they understand that there is somewhere for them to go or a person to see, where before an eruption takes place, which is really a form of communication to say "my needs are not being met and I don't feel safe".

So that's one issue in that particular space, but I think across all settings, we just have got it all wrong. We're really looking, obviously first and foremost we've got to look at it as a breach of human rights in accordance with the UNCRPD [Convention on the Rights of Persons with Disabilities]. It's a form of torture. But it's also a perceived problem from the people that are using the restrictive practice and the people that are permitting the use of that restrictive practice. So by that I mean it's the perception that there's something wrong with the person and that they are, those deeper, subconscious biases that people have that a person with a disability is a menace, that they are violent, to just automatically make those negative assumptions, it clouds how we perceive that person and then it affects how we act with that person.

So, I think we really need to dig a lot deeper and ask more questions of service providers, ask more questions of them about what are they doing to actually deeply reflect upon their actions, what are they doing with the conditions that they're providing for a person with a disability to ensure that a particular reaction, which is often a well-known reaction, continues to take place and why do those conditions continue to stay - remain as they are - whether it's the space that they're in, not having the right person with them, continuing to put them on a bus, for example, if that is a trigger. There are so many things in so many spaces where we're looking at it in the wrong way entirely. This sort of blame game, I guess, rather than looking at what is the service provider's responsibility here to look deeply beyond seeing that person in that negative way.

I know we hear of families that come from... especially when they are transitioning, say, from a segregated setting to a day program or an ADE [Australian Disability Enterprises], they come with a file this big because of all the violent things that they've done, and that colours and affects the perception of the person that is going to be interacting with them in that next phase. Very often, if we just take some time to really deeply get to know that person and what it is that their needs are and meet those needs with the right conditions around them, the violence dissipates and often is just completely removed."

NSW Advocate, March 2021 Zoom workshop with DRC

"...the medical model is the first go-to for people. So people have got a 2-year-old and they are going this 2-year-old [is] not doing things other 2-year-olds are doing. They go to their GP and that's how they get into the medical model at a very, very early stage and they're not given information about their child and how their child might develop over time and the different kinds of things that they might have to do to adjust their lifestyle. And from the very first get-go, you're having very young children going on to medication. To my mind, that's one of the places it starts. So by the time they're old enough to go into a group home, they have

been on medications for decades to 'control', so-called, their 'behaviours' because that's the starting point. I don't mean that to sound like a blame. I think parents are struggling with "what do I do with this small child?".. how am I going to adapt? Then, of course, you go to your GP and doctors think in terms of medicines. They don't think in terms of behaviour modifications. That's not their training. So from my point of view, where the system could be improved drastically is better training, better training from the get-go from medical staff being able to appropriately refer very young children to more behaviour-based, and training for parents so that they know how to guide their small children so they don't end up being 15-year-olds that punch holes in walls."

NSW Advocate, March 2021 Zoom workshop with DRC

For comments on the experiences of children and young people with disability in relation to Child Protection Systems, see [Section 12: Children and young people with disability](#).

Section 12: Additional quotes and examples from advocates

"I just think about exclusion and, sort of like, access to services and things in terms of poverty and all of those - I'm thinking just generally. It's not really about a specific example about restrictive practices but just that access. For example, NDIS services, and how complex that can be and particularly, I have had experiences with people with psychosocial disability who can be excluded on many levels, just because of the complexity of systems, to actually access support that they need. So I'm just thinking in terms of arrangements and service arrangements and how people are excluded."

NSW Advocate, March 2021 Zoom workshop with DRC

Theme – Systemic power imbalances

"...despite all the legislation, the principles in our acts regarding decision making, the Queensland Human Rights Act, the NDIS legislation, the principles decreeing choice and control, prevention, protection from abuse, neglect ... our system each and every day unfolds very differently. The daily oppression, the harm being caused is largely hidden. It can be subtle, or it can be so clear and in your face that most of us would find it hard to believe that it could actually happen, but it does.

I think we have to think about how and why the mechanisms to protect the system itself are still far greater than the very weak mechanisms that exist to protect vulnerable individuals or the nondominant groups, and I would suggest that advocacy workers are part of a nondominant group which the dominant groups try to control. As an advocacy worker, I'm forced to work in this arbitrarily set system of social hierarchy which includes our government

institutions, such as QCAT [Queensland Civil and Administrative Tribunal], the office of the PG [Public Guardian], our health institutions who often become the oppressors when they're supposed to be the protectors.

I've had repeat experience of how this powerful system obstructs and attempts to diminish the rights of people and also the advocacy work that I do and the role I'm meant to fill, and I shudder to think what the system would get away with when there's no advocacy worker.

I think we need to identify the power dynamics of the current system and identify who those dominant power groups are and hone in on just how this institutional abuse of power and oppression occurs. We really need to understand those two things that I've mentioned.

...There's been a number of times where I've had to stand up against a very scary system to prevent something really bad happening and I'm involved in something this very day as we speak which is very difficult, but advocates must be able to perform that role without the added difficulty of this power imbalance ... that we work within the system and we have to identify how this power imbalance is occurring and identify... hone in on how it happens because it's difficult.”

QLD Advocate, April 2021 Solutions focused workshop with DRC

Theme – Inadequate cultural change and staff training

“One of the biggest factors we see between people in more problematic areas is the attitudes of the staff and the management working there, so when they see the people that they're working with as an individual, as a person, then we don't see as many problems. When they see them as a problem, as a behaviour challenge, as a job, then that's where we see more restrictive practices, more abuse, more violence, and that is something that sometimes comes from the head down challenge of that organisation, that particular organisation, and their views on the people they're working with and sometimes it's an individual.

That's something that if we were to have, I know in the aged care settings they have an agreement where people have to do some education about attitudes with an advocate or with an organisation that has an advocacy focus. It would be ideal if that was seen in disability settings as well.”

WA Advocate, October 2020 Zoom workshop with DRC

“...it's become a culture, actually, and that often, and I'm speaking really probably in the supported accommodation, so it kind of crosses over around that segregated sort of, or secluded sort of places. But there doesn't seem to be strong leadership within a lot of the houses as well. Like there's some models out there that have a very big gap between the boots on the ground to the management. So the manager might manage five houses, but

there's no one actually on the ground, actually working with the staff, actually giving that sort of mentoring or that sort of leadership to make sure that things are happening.

I think one of the big questions that I'm constantly, we're constantly talking about in our office, is that it's relying on good staff to report this stuff as well. We're relying on people being honest with this stuff. They're going to protect themselves. It's very subjective.

I recently had a conversation... with an organisation, around a behaviour support plan around restrictive practices and the conversation went like ...that it's reliant on ...that it's a process... that they're following through the behaviour support plan... that we've tried all of these strategies and we're using this as a last resort. However, we're reliant on people being honest to do that and I don't trust a lot of staff in saying that they've actually done all the strategies prior to just popping a pill and thinking that that's okay, or locking a door because they don't want that person causing any sort of ruckus.

So it is that control, that power and control, over our most vulnerable people that are in systems, that they don't know any different. They can't say, "I'm really upset because", "And I need to go outside out into the garden". They will, if they're non-verbal they'll bang things, they'll try to say to the staff who aren't taking the time really to get to know that person, about why they're doing that behaviour. The whys are never answered.

When somebody is behaving a certain way, don't just assume that, "oh, they're going to go off track and they're not going to be okay." There's not a lot of consultation, I don't believe, with the staff, with their management. Management have it all perfectly written out. They have it all detailed, everything looks wonderful on reports, but the staff on the ground have no idea these things are in place and there's no communication down below..."

VIC Advocate, February 2021 Zoom workshop with DRC

"You can get some really amazing staff, but the problem is that, because they are so amazing, you request them with your clients and then they burn out. I guess management need to look at the ones that need to be upskilled and provide more training, because I think there is a lack of training and education around particular areas, especially around behaviours where staff just don't have the skills, and they haven't been trained to be able to deal with some of the behaviours and the intense behaviours that they are expected to deal with. And then, when something goes horribly wrong because they haven't had the training, it's their fault, as opposed to being proactive and making sure all staff in that particular house have the training for the needs of those clients."

QLD Advocate¹⁶⁴

¹⁶⁴ QLD Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

"I have ... seen situations... where new staff come into organisations, see various ways of working, working with people and in fact it's learned practices and 'this is an acceptable way of working', responding to people and almost the accepted norm and that becomes very difficult to challenge and to relearn more positive strategies for people with disability."

SA Advocate, December 2020 Zoom workshop with DRC

"...often when you're getting into the more complex areas of behaviour support, having a dedicated team that is trained as well to be able to implement those plans to the extent that they're supposed to be, I think is also another issue that affects the effectiveness of those plans, other than sometimes those plans not being adequate enough in terms of the data that's collected around behaviour, and I mean in terms of the function of that behaviour that they're trying to support or manage as well. So there are some inadequacies in the system itself that makes those plans ineffective or less effective than what they need to be as well.

So you've got those issues as well as the - in terms of the level of training of staff being able to correctly gather the data to give back to the specialist so that the specialist can make changes to the plan in time is also another issue. So there's a level of skill that the staff need that seems to be lacking as well. So not only is the fact that staff aren't remunerated to a level that is I guess commensurate with what they're doing in terms of the level of skill required, and then the training that they need, and also to be able to understand those plans and what the actual purpose of them is, I think I've found as well."

QLD Advocate, December 2020 Zoom workshop with DRC

"A lot of clients I do submissions with might be talking about a more specific issue around a job service provider but what they actually want to discuss is systemic problems with that system and what they've experienced over the years. It is relevant, especially when people are engaged with them for a long time and there are signs that the provider has had their patience tried and communicated differently with that person because they are frustrated in the situation and being stuck with what they are doing with that person. That is around the way people with disability are communicated with and that is relevant."

WA Advocate, "Advocates Zoom In On... Barriers to Employment" October 2020 Zoom discussion

"...I think there's lots of things that need to be done to work on improving the situation. I think what a few people have touched on here is that in many segregated settings you're in this closed environment where there's a limited amount of people involved and seeing the situation and they may have negative attitudes, but also, they may also just be unaware that what they're doing is not okay or unauthorised.

...[that] history of restrictive practice and it being normalised in the disability sector as something that you just do and it's just a tool and that is really still ever-present and widespread in many spaces, even with NDIS coming into the picture and putting into place, you know, many, kind of like, clear descriptions of what restrictive practice is, authorised, unauthorised. But in many group homes I've seen staff members and even house supervisors just really not... it's just not computing in their head that what they're doing is restrictive practice and that it is a breach of a person's human rights if it's not part of a behaviour support plan, if there's no positive behaviour support practitioner involved.

I had one sibling of a resident call me about one issue of abuse occurring in the home and she just happened to mention that the resident had also had her electric wheelchair taken off her and had been put in a manual wheelchair and I followed that up, but that wasn't her inquiry or concern that she was even raising and her, the sibling, wasn't aware that if that wasn't authorised that that wasn't okay, and it was only when we followed it up we found out that it was absolutely inappropriate for the house to be doing that and it was not an appropriate restrictive practice to be used.

So just that kind of closed segregated setting, people that have their eyes on that setting maybe not necessarily being aware that what's happening cannot happen and isn't appropriate and therefore risk of it just perpetuating and continuing.”

VIC Advocate, February 2021 Zoom workshop with DRC

“...[another] advocate previously mentioned about lack of resources, lack of training and support for staff I'm seeing really unqualified, and I don't want to generalise...but I'm gathering a sense of the wrong qualifications and people being in certain settings with power, and I think what happens is when you don't align the right people with the right skill sets and qualifications with the importance in these services and settings, you create a cultural inequity. We create it's a culture of... not seeing people as assets - that includes staff members, that includes managers, that includes also the people with the disability. So not putting them at the centre as human beings and having a right to a safe, equitable space where there is potential for wellbeing and growth. I think from my experience it's very much a sense of there's a structural problem, there's a systemic problem, and there's been research. And the Royal Commission at the moment is doing so much work in gathering the data and information in targeting these gaps, but nothing seems to be really being done on the grassroots level.

I think as long as staff in every capacity, whether it's on the ground, you know, frontline workers, or whether it's advocates like us or management - if there isn't the right qualifications and training, if we're not being taken care of and we're not constantly trained, whether it's cross-cultural training in disability or what have you, there's always going to be systemic problems in the sector. And I think for me, what I would like to see is, more emphasis on organisational responsibility for addressing those issues, systemic issues, and also families

need to be, families that are working with the children or with the clients, also need to be respected. There are some instances yes, there is some abuse with family members, but I also see a lot of family members are being neglected and abused by the system as well.

So I think... it's very complex from where I'm standing at the moment...I do feel sometimes very frustrated when I am challenged with a systemic issue, with a service that just basically like I've heard so far... 'it's too hard', 'we've done what we can', and the onus of responsibility is always back on the client who is in a very vulnerable position..."

VIC Advocate, February 2021 Zoom workshop with DRC

"...under the NDIS, I am not sure that service providers get paid to do training and I think there's an economic incentive to have agency staff and untrained staff and that's part of what privatisation of this service causes. So there is a real problem with training.

Our client group are people with intellectual disability and especially, it concerns me, people in group homes. Our service has many incidents where the police get called in because untrained staff are not familiar with the clients or they're not familiar with de-escalating clients by just providing consistency in the same service each day. And what you get is that the client then has a behavioural reaction and then, because they're untrained, they call the police and our clients end up going to gaol."

NSW Advocate, March 2021 Zoom workshop with DRC

"I just wanted to say that I think cultural change in these very large, long-established organisations, who've been delivering support to people with disability, is a huge struggle. You see the same workers are there that have been there perhaps for the last 15 years, when they were supporting people with disabilities in very restrictive ways and choice and control was certainly not on their agenda - person centred, flexibility, responsiveness - none of that was on their agenda.

It's a bit like asking for cultural change in the police force in New York. Some of them are talking about let's sack them all and start again, and countries have done that in ways with their police force, and I feel like that's almost what you need with some of these large services. I don't know how you can effect real meaningful cultural change with people who've been working in a way that's so restrictive for so long and it's embedded in all of their practices. They learn how to speak the language, but they're not delivering good support to people with disabilities.

So we just blacklist many organisations and will actually recommend people don't go anywhere near them because they're so bad. And as advocates, we have to be very careful about the options and choices that we give people so that they can decide which service or supports or approaches they want, but we find that quite difficult because many of them are

just not suitable and we actually strongly recommend people don't have anything to do with them.

We've tried to advocate for people in those services in the past. We've gone through State Government complaints systems to try to effect change, and we've had staff from those big organisations come to us and make complaints about what's happening, whistleblowers, about what's happening in those services and all that happens to those staff is they lose all their hours. They suddenly have no shifts when they report things to their supervisors about what they see, you know, very concerning abuse and neglect. So, yeah, I don't really know how you effect real change in those large organisations... I don't have any answers.”

QLD Advocate, April 2021 Solutions focused workshop with DRC

“With regards to good cultural change, I'm sorry, but I can't think of anyone. Unfortunately, when advocates get involved, it's usually because of problems and we're talking NDIS systems with service providers that are not doing the protégé, person who needs an advocate - stuck in a bad situation, so the advocate is trying to deal with providers... not good examples of service provision and good culture, and so it's hard for advocates, and even our program as a coordinator, to be able to see changes at individual settings let alone across an organisation.

It's just like oh, I'd love to see that happen, but my impression is it's smaller niche-type providers that are more interested in doing what the NDIS is aimed to set up to do, which is provide that high level of service, which is really trying to improve the lives of people rather than fit them into the organisation's way of doing things. If there's a big provider out there that can change after an advocate has been involved, I'd love to see it. I'm more and more convinced it's going to take a systemic change through the Royal Commission...”

“It often seems to be financial barriers. There is often good will with providers, but they are always constrained by funding.

We find that service providers don't have the resources for good practice, so they just cope as best they can. We also find that they will take direction from plan nominees due to fear of losing funding - and this can create situations where service providers are clearly colluding with restrictions and abuse, but fear of loss of funding seems to drive the behaviour.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“Here in the NT, larger providers and how much, as a percentage of their overall budget/funding, they allocate to their ongoing staff development and support in residential and outreach support (SIL, day program etc) is often more about lip service or severely compromised.”

NT Advocate, April 2021 Solutions focused workshop with DRC

Lack of choice and control

"[NSW advocacy organisation] are doing training for us, and for me to pass on to citizens and advocates about supported decision-making to what we find, in particular in the Citizen Advocacy program, a large percentage of people are non-verbal. They are overlooked in the decision-making process. They are just not getting their voices heard in any way. One of the issues is, it comes back to the staff saying – the very people who should know them the best and should empower them are actually – I understand they have many masters, and they are doing what the service needs doing, or done. But it just really negates the voices of the people who should be empowered to make the decisions. Restrictive practices is one that comes up, 'We need to get a guardian in'. So you completely remove any say from the person, whereas with more time spent, the opportunity to hear – and sometimes we all know, nobody wants to live in place with a dangerous situation, but sometimes there are other ways. It's that leap to the most restrictive thing, that I find most confronting. Maybe, ultimately, that is what we're going to do, we're going to have a substitute decision maker, who probably doesn't know the person and will make [decisions] based on the evidence. It's not that they're making bad decisions, but can't there be some other steps before we leap? Honestly, it's from the first proposal... There's an issue I'm dealing with at the moment with overeating. It's like 'I'm not agreeing to that', this man... is making it fairly clear that he is not giving consent to what they want done, so let's take the steps along the way. Don't leap to that point where he is completely disempowered, it's back to that rights-based thing. His rights are just negated. That is their first step. We are not unreasonable people. Advocates obviously don't want to do any harm but it's very common... particularly people who don't communicate in the standard verbal ways, it's like 'he can't express himself'. Well actually, he can. If everybody was trained in the rights-based [approach]... and facilitating people making their own decisions, maybe we wouldn't have to leap to that."

NSW Advocate¹⁶⁵

"...the support that's in place for people, they are very roster driven, and I think what we've got [when] the NDIS came along. What we hoped to see was the going away of block funding, but I think that what we've got effectively is the continuation of block funding. And so we see this happening in group homes, all sorts of congregated settings, where what's being delivered to people is being delivered to a group of people rather than being delivered to individual people. So what people are receiving is a service that's aimed at people with disability, not a service that's aimed at Jenny or John or Tom or Bill.

So there can be... we want this to happen for people, that is the whole idea why we've got an NDIS, because we want to see that people are able to live better lives, and you can't live a better life if your life is contingent upon something that might happen in the congregated

¹⁶⁵ NSW Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

setting that you live in. So, for instance, you've got somebody who really loves to swim and is on a schedule of support, and during that week that person is scheduled to go swimming on Thursdays at 2 o'clock. So Jenny is really excited about going swimming at 2 o'clock on Thursday, and then Bill for some reason has a really bad day and so support says "We can't go out of the house now", so Jenny misses out on going swimming. Jenny misses out on going swimming and she then has a reaction to the fact she can't go swimming because she loves it, it's something very calming for her, it means she's out doing things, and she is now restricted and forced to stay in her house.

And this happens over and over again. We see it happening that people have got schedules of activities that they never get to because the model of support denies them the opportunity to do that. So what then happens is that Jenny starts to get a reputation as somebody who's very difficult to work with, or in fact a reputation that Jenny doesn't actually like going swimming because she has a conniption on Thursdays when swimming is supposed to happen, and the kinds of things that happen for people is that Jenny is now anticipating that she's not going to get to go swimming, so she starts to have a bit of a conniption before swimming, whether it's going to happen or not, because that's a pattern that she gets to experience and that gets reinforced week after week after week. Then we end up with a positive behaviour support plan which ends up on a shelf and Jenny still doesn't go swimming on Thursdays.

So we need to get rid of this kind of service delivery which is about rosters. Rosters are the things that keep people tied to their homes, it denies them opportunity to be out doing very ordinary things. And the NDIS, we know as advocates, I think that you would all know, that the kinds of supports that come, and talking particularly about supported independent living (SIL), what a misnomer that is that people are in these SIL arrangements and those SIL arrangements only. And I've just been talking to somebody yesterday who's in a SIL arrangement, and their SIL support only provides for in-home support, going to a doctor's appointment, and going shopping, that's it, and there is no other support available to them to be able to go out and just do the ordinary things I do. I go out and have drinks with my mates on a Friday night. All of those kinds of things are not available to people. If people were able to live better lives, we wouldn't be having these kinds of things happening, we wouldn't be having to tell these stories to the Royal Commission, we wouldn't have to be constantly advocating for the same thing day after day, week after week, month after month, decade after bloody decade.

...I'm sure in some situations it would be about money, but I think actually what it's about, a lot of it, is about mindsets and that even people who live in SIL type arrangements and they've got money in their plans for community and civic access to the community, et cetera, that doesn't get used in that way because, again, what often happens is that SIL arrangements. So when they've put their quote in, they've quoted for social and community participation and so there's some additional money in there, but their mindsets are that we do that, and so unless it sits with a different provider, then very commonly it doesn't happen because that money gets used up in some other way.

Now, I don't know the accountability around those things, and it's very hard to really get a handle on some of this stuff, but it is our understanding that quotes go in, money is allocated and then services just get that money every month. There's no accounting for it in any particular way. So even if there's money in there for social and community participation, that is no guarantee at all that the person will get access to a support worker to take them out, because they only have workers from the roster or very occasionally... another young woman who has got this additional money on a Thursday and her SIL provider fills that up with appointments and she says "I just want to go and hang out at the shopping centre" - she likes to go window shopping because she doesn't have a lot of money - but they put in other things so that now, what was really the responsibility of that in-home support, has now been transferred over to social and community participation which is about going to appointments.

So that woman has contacted us on a number of occasions about these kinds of things and so the service provider says, "Oh, yes, well, we couldn't make that appointment on a different day because that was the only time that the doctor was available." Well, then make the social and community support on a different day that suits her. If you can't possibly go to the doctor on a different day and this is a usual appointment, then you need to negotiate that stuff, but they don't. So I think that there's a mix of people perhaps not having enough funding to do that, but also that funding is not being used in the way that it should."

SA Advocate, December 2020 Zoom workshop with DRC

"...while the NDIS' intention is meant to be individual based and really look at these things, the administration doesn't work that way, and to me it's really evident in a way that the NDIS or NDIA is very happy to fund group setting bowling, but if someone wanted to go out with their friends bowling that's an out of pocket experience. And to me that really shows that they're continuing to fund the same thing, and this is where the cost is coming in.

I've had a couple of instances where I'm trying to separate out that SIL [supported independent living] and get two different providers in to provide different support. And it has been two years to negotiate that, and has had to involve higher up people in the NDIS because the people at the bottom who do plans don't understand. In my instances, the support has been cheaper. SIL is an over-delivery of services that someone doesn't need, and then what will often happen is you need more money to actually get support you want and need. Whereas, if they just really have a look at what the person wants to do and then do the SIL afterwards, you're probably actually going to find it's going to be about the same if not cheaper. It's just this wanting to ensure that they have this income coming in.

I think it's very service based, even the process of producing a SIL is very service based. They get to put in what they want, the NDIS don't question, and when you challenge in an internal review, they kind of go, well, you negotiate the service provider. And there's no power there to do that, especially for someone who has an intellectual disability, who is continuing to live in the home of the support they provide. They're going to hear negative feedback about them challenging, wanting to use a different service.

It's just not conducive of individuals. There just needs to be certain things in place that are done differently in the administration to allow for some things to happen. I said that example of the bowling - why will they come bowling as a day option but not if you want to go join a local bowling club. To me that really shows the true colours of the administration of the NDIS."

SA Advocate, December 2020 Zoom workshop with DRC

"I think in effect guardianship can, when misused, be a form of restrictive practice in and of itself. We've had a lot of reports not necessarily of guardians, although sometimes guardians, but more frequently public administrators of kind of overstepping their authority and restricting the client's access to their own finances, and keeping information from them that would be used by the client to be better informed on the way that their finances are being handled and, yeah, we get a lot of those come through on a regular basis."

TAS Advocate, November 2020 Zoom workshop with DRC

"...when I've seen things happening or people have raised concerns with me, it's conflicts between residents because there's no choice. They're lumped together with a group of people they've got nothing in common with - had no choice who they live with, no choice in the staff that work there. It's not a home. It's their workplace, you know. It's all taken away from them. And often staff are too busy and [there is] big turnover of staff."

TAS Advocate, November 2020 Zoom workshop with DRC

"I think what I've seen in service delivery in those big group homes, or large living arrangements, conglomerate living arrangements, is that service providers are really, really preoccupied with their systems and how they're going to make their systems work within the NDIS, and then how they're going to make that system look like it fits within the choice and control kind of paradigm. So I've seen services saying, "You can't have those extra hours of support to do this thing because your NDIS plan won't allow for it." Now, when I've talked with an LAC [Local Area Coordinator], they've said, "No, no, they've got lots and lots of hours left." It's really about the service not wanting to go back and do an extra, amend their service agreement, all of that extra admin."

I've also seen people who have been promised a particular selection of workers, so you'll have your own workers, you'll have your own team, it will all be about your preference, and so people saying, "Okay, can we interview my team?" "No, you can't, you can have a choice between these people because they're the ones that have got that line free." Then we can't guarantee that that team will stick with you because we might have to send them somewhere else, and you can just about guarantee that as soon as somebody has got a stable team that is wrapped around them and working well, some of those team members are identified as being great so they've got the ability to go and work with someone else."

So that is a pattern and coming from service delivery, it's something that I was always fighting against. I've seen that really, really ramp up since the NDIS has been introduced."

TAS Advocate, November 2020 Zoom workshop with DRC

"...it's a real worry to me that the language of the interactions that there actually are around, not only around ADEs [Australian Disability Enterprises] but the whole sort of areas of restrictive practices too, and ... it's consequences, it actually isn't about restrictive practices. I'd say exactly the same thing, that people are actually told that it was their choice or they're presented with choices only that are acceptable with the service provider. So it really actually isn't a choice. I mean, it's not - it's a sort of blue socks or red socks and that kind of thing, not really bare foot in the sand, running along the beach. I think that there's a lot of things around communication and its connection with people's values."

TAS Advocate, November 2020 Zoom workshop with DRC

"...unless the workers or the organisation or the service provider...is actually going to offer advocacy and actually explains to people that they can access advocacy, then it's controlled by the dog at the gate. ...I find that when we talk about choice and control, I get sick of hearing about choice and control because I don't believe conversations are had with people around their choices and control. So it ends up being, "Oh, but that person has chosen that jumper." Well, of course they've chosen that jumper, but did you have a talk to them about it's really hot outside and that it may be really dirty or it may be really old or it's been shrunk in the dryer? Did you have those conversations? Because everybody wants to do whatever they want to do, but unless someone really has these conversations with people, it's just - it is guarded very carefully about any sort of complaints. People don't know that they can do it."

VIC Advocate, February 2021 Zoom workshop with DRC

"...during the planning process day program, quotes are approved without question, no thinking outside the box, no other options offered or thought about"

VIC Advocate, February 2021 Zoom workshop with DRC

"There's one area of the relationship between day services and day programs and group homes where the landlord is also the provider of the same services, particularly if the person in the group home is not eligible for the NDIS. We recently had a case where someone who wasn't on the NDIS was over, well over 65, wanted to retire from going to day services and he was restricted from doing so by his landlord, who not only was his landlord, but was also the service provider that provided the day programs. He was not able to retire because they wouldn't provide a worker to be in the house with him during the day and there were no funds for him to go out in the community to what he didn't want to do in the day services."

It's a gap that has fallen through, where you have a conflict of interest where the same service provider is actually the landlord and the person is over the age where they don't qualify for the NDIS. They're stuck because most of their pension goes towards the accommodation and there's no money left to employ a worker to stay behind, allegedly while that person is able to go out, say go to the museum. He wanted to go to museums, wanted to go to concerts, he wanted to just sit in the middle of Federation Square on a sunny day for a couple of hours. Not allowed to do it.

He wanted to retire from going to the day program, but he couldn't."

VIC Advocate, February 2021 Zoom workshop with DRC

"...the day staff are actually controlling individuals' lives. This particular family has now moved to the [VIC city] area because they've been unsuccessful in challenging and making life better from where he was living. I'm also finding that a lot of the staff are still very archaic in the ways that they're running the day service. So the day service provides the programs, not the clients providing the programs for what they would like to do.

And the other thing is staff are out there doing what they want to do and dragging the client along. So an example is, 'My child is in the Little Athletics swimming competition today, so we're not going to do the cooking program, but we're all going to go and sit and watch my child swim today.' So the clients are paying for a service and the day services aren't providing them with their choice, control and the activities that they wish to participate in."

VIC Advocate, February 2021 Zoom workshop with DRC

"...or the classic of going to do the sw's [support worker's] personal grocery shopping - which is called "capacity building"! following someone around a supermarket is not capacity building! ... We need more focus on the possibility of small business setups by pwd [person with disability], rather than just going to day program to paste icypole sticks together."

VIC Advocate, February 2021 Zoom workshop with DRC

..."or community access with a SW [support worker] - going to visit the SW's aunty for a cup of tea."

VIC Advocate, February 2021 Zoom workshop with DRC

"...and we see this all the time where, for instance, somebody has an amount of money that's in that roster which is their one-to-one support that they get and it's rostered from 5 o'clock to 7 o'clock every day. Well, what if I want to go swimming at 9 o'clock in the morning? What

if I want to do something elsewhere, I want to do that on my own? The roster doesn't allow for that.

Not only doesn't it allow for that, but if you have, let's say, swimming scheduled into the roster and the roster is the support staff and you're going on Tuesdays at 10 o'clock, if Fred, who you live with, who you don't actually know, but just somebody who lives in that house with you, has a really bad day, then those two support staff that are rostered on have to stay at home so you don't get to go swimming. All of these things over and over and over again are just a reflection of the old bad, sad, terrible block-funded model that creates the environment in which people experience violence, abuse, neglect and exploitation.”

SA Advocate¹⁶⁶

Reliance on restrictive practices to control “behaviour”

“Restrictive practices are widespread amongst the disability population when there is considered to be a behaviour of concern that could lead to harm to persons, whether that be the person themselves or others. In some circumstances there are restrictive practices to prevent damage to property. Restrictive practices... should be a mechanism of last resort and as temporary as needed for the person concerned. The most widespread use of restrictive practice is medication, otherwise referred to as chemical restraint. From my experience, this is the first go to for families and services, especially when there is a sudden onset of challenging behaviour. Medication is a medical model of care and often this would not even be considered by families as a restrictive practice. There is limited (in my view) supervision about the use of this sort of practice and little consideration of when there would be an end point to the practice.

After medication, I would say the second most widespread range of mechanisms or practices are those that limit people access to spaces/places where it might be considered the person would be put at harm if they can access that space. High walls, locked gates, locked cupboards and fridges. Regularly keeping everyone with a disability in environments that restrict movement even if there is no reason for all of the individuals in that environment to be restricted.

Systemic support related restrictions, where disability services do not build into programs adequate flexibility of support to allow a genuine freedom of choice of movement for people in care. For example, simply not taking people into the community based on staffing numbers or perceived difficulties getting about. People with disabilities being persuaded or activity discouraged to go out because of the efforts this would fall on paid support workers.

Another widespread restrictive practice is used on people who cannot move themselves - moving people who cannot move themselves to places where they do not want to be. In

¹⁶⁶ SA Advocate, April 2021 Solutions focused workshop with DRC

particular, people in wheelchairs who do/may not have good verbal communication. The last two are least likely to ever be even considered a restrictive practice.

*NSW Advocate*¹⁶⁷

“I don't think that we're seeing a lot of change at all, to be honest.... a lot of times it seems to be that the practices are implemented because it's convenient for staff, it suits them and it's obviously a way of controlling the person. ...I've not really seen much reduction, if any, in the use of restraints.”

VIC Advocate, February 2021 Zoom workshop with DRC

“In many cases I have had, there has been 'indirect' restrictive practice to a person due to environmental restrictive practice needed for another person in a group home.”

VIC Advocate, February 2021 Zoom workshop with DRC

“...my sense ofa bit about restrictive practice, and this is a little bit more historical, is that sometimes it is coming from a place of control or a place of what is best for staff or what is best for the environment, for example, that people might be a part of, whether that be residential or another environment, rather than necessarily being viewed as what's best for the individual. And I think there's been some historical culture around that restrictive practice is just another tool or another approach to take when working with people with disability and it's never been seen as something that's a breach of somebody's rights.

So I think some of that is changing, but my sense is, because of that history, because of that understanding, it can very quickly lead to experiences of abuse or neglect or issues where more power and control is influential within that relationship or within that environment.

And I think, sadly, that can also include families as well, where chemical restraint, in particular, is seen as being something that's just part of the everyday practice and I think there's a real concern about changing from using chemical restraint to looking at environments that are influential to behaviour support.

...the change is very slow, but I think because of the increased oversight, there is vigilance, or there's greater vigilance, and there's more dialogue in understanding what restrictive practice is. And because they need to appoint people in the organisation if somebody is on a BSP [Behavioural Services Program], or restrictive practice, where that type of oversight wasn't previously there and, you know, there's monitoring that's occurring. So I think that there's a few more measures in place that are making people aware, so I hope it's a pathway for greater understanding around restrictive practice. I'd like to think.... that even the subtle

¹⁶⁷ DANA's 2020 Restrictive Practices survey, Response from NSW Advocate

things that actually occur in environments is called out as abuse, neglect, exploitation, you know."

VIC Advocate, February 2021 Zoom workshop with DRC

"We find it across all age groups and lots of different sectors, from kindergarten, preschool, in mainstream education, to special education settings. We find it in group homes, we find it in aged care settings and we find it in private residential situations and family situations. So it's across the whole sector. It seems to be focused more and more on people who have complex, challenging behaviours associated with their disability, and it's the inability to manage those complex, challenging behaviours and the lack of support and training for people, service providers, parents, schools, teachers, whatever, that is largely the problem."

VIC Advocate, February 2021 Zoom workshop with DRC

"I think in some family situations as well, because I think the problem actually needs to be looked at from a whole-of-life perspective, and the reality is that the trajectory for these individuals is that they're living at home, their behaviour is becoming more and more challenging, you know, there's all sorts of dynamics going on in the home. It eventually leads to the family reaching out for some sort of support and that not being great. There's certainly nobody standing beside them saying, "Look, when your son or daughter does this, this is what it means, this is how is probably the best way for you to respond" or they're not saying, "You see what he did there, that's an early sign of escalation, this is a great strategy." There's not a lot of that across the board.

So that then leads to these individuals ending up in supported accommodation in a very rushed way. They have no rights over where they go, how that process occurs, who they live with, what's done to them. There's just no control over any of it. So if we take away their disability, of course anybody going through that will end up with posttraumatic stress disorder as well as whatever their condition is.

So I think the problem is quite complex, and my experience is that I've actually never come across a service provider yet who's able to respond to that in an effective way where the outcome for the individual improves their rights, and reduces the use of restrictive practice. I have a client at the moment who has lived in a group home, he's in his 50s. Somebody else has been moved into that environment and keeps assaulting him and his sister is advocating, and the restrictive practices are going on there big time. He's stressed out, so he's being medicated. And these scenarios are repeated over and over again in supported accommodation.

So it's complex, it's a systemic issue, ...service providers just kept walking away because it was too hard, and I'm aware of some other families because I run a peer action group at [VIC Advocacy Org], and there's certainly other families who have done the same.

I'd like to see some of the tertiary institutions doing some research projects around these issues and coming up with solutions - solutions for families, solutions for providers - because right now, and certainly since the NDIS, I'm seeing more resources. I'm thinking of one young person I'm supporting, there's a very reputable behaviour support organisation involved and there's some great reports that have been written, but it's not actually playing out at the coalface of the support, and there are lots of transient workers. It's problematic. So I'm seeing a lot more resources in some respects, but it's not leading to the outcomes that it should."

VIC Advocate, February 2021 Zoom workshop with DRC

"I would also mention another setting increasing the risk of restrictive practices, particularly seclusion through lack of access to supports and failures to act, would be in aged care facilities (for both younger and older people with disability). With low staffing levels and a lack of expertise in spinal or neuro care, many nursing home residents are often left disempowered, with only recourse to a bell at the side of their bed to seek support. Many aged care service providers misinterpret peoples' needs and fail to appreciate their choice and control. Many people do not have the choice of chair that they use and many unscripted chairs cause pressure sores and present other health risks. It's particularly concerning for older people with disability as they often do not have support persons to advocate on their behalf."

NSW Advocate, March 2021 Zoom workshop with DRC

"...more often than not the use of restrictive practices indicates poor quality supports, support workers who don't know or understand the person, so they cannot interpret what the person's communication is trying to convey. They misread the person, they try to control them, and quite often, because they don't have those skills and they don't have that relationship with the person, the fallback position is "we need to manage this so we'll use restrictive practices," and once that starts, then of course you've got a clinician writing these things. And... it often happens with the bigger services doing it in-house because they've got their own psychologist, so they wrap up the person, they often provide all other supports as well. It behoves them to have a huge plan then around a person so quite often a reputation that is completely undeserved is built up around somebody simply because people don't understand them."

QLD Advocate, December 2020 Zoom workshop with DRC

"They have the effect of isolating people, of making them even further disadvantaged because they are either, the restrictions are so restrictive, obviously, that it makes people's lives , basically it makes people's lives miserable. You know, they have very little... anyone who's on a restrictive practice appears to have very little opportunity... for supported decision making, to really participate in decisions that affect their lives because they tend to encroach

on other areas of their life as well I think... I would say, for people living in group homes and those sorts of settings, there would be an extremely high proportion of people who have unauthorised restrictive practices, you know, probably 80%... and they don't even realise that they are subjected to restrictive practices."

TAS Advocate, November 2020 Zoom workshop with DRC

"...restrictive practices are around every aspect of daily life in group homes. you need to shower at this time because that's what suits the staff. you will eat at this time etc. daily routines are regimented and based around ease for staff"

VIC Advocate¹⁶⁸

"It's kind of developed this dependence on [restrictive practices] and medications to manage behaviours instead of like, a last resort, you know like we were saying before it just becoming normalised, which isn't great for the individual."

SA Advocate, December 2020 Zoom workshop with DRC

"I wanted to also raise the issue where for people in group home situations or more institutional settings, there seems there may be more pressure on services to seek guardianship orders for people that may not have had one in place, so that they can be within the guidelines of having restrictive practices in place, and how that sort of is affecting people's experience of guardianship overall. And also, maybe take some of the pressure off services to actively work with people around skill development in some areas where instead the restrictive practice is put in place. So like locked houses, for example, where a person might be able to be supported to learn how to be a bit street smart, but instead a restrictive practice is put in place through guardianship."

SA Advocate, December 2020 Zoom workshop with DRC

"Restrictive practices are quite often used inappropriately and that, aside from the very obvious physical injuries, can lead to issues, long-term issues with mental health and wellbeing. There's the possibility of, I guess, escalating unmet needs if behaviours aren't addressed appropriately, which then can lead to that labelling of a person as being difficult or aggressive, quite dehumanising.

It means that we've seen in some cases that inappropriate restrictive practices leading to those labels has meant that people are unable to actually engage with services because providers don't want them, they're too challenging to provide services to, so all of that ends up snowballing into a situation where people are further isolated. They don't have the

¹⁶⁸ DANA's 2020 Segregated settings survey, Response from VIC Advocate

supports that they need, and we know that that isolation obviously increases the chances of violence, abuse and neglect and that quite often restrictions are put in place based on that 'what if' perspective, so that duty of care versus dignity of risk, and risk is fundamental to the human experience. The ability to make risky decisions, it's part of learning and growing, so when we're denying people those opportunities, we're denying them the human right to learn and grow and have those natural things that every one of us should be able to experience.

So it's not just, I guess, the physical response, it's also those bigger picture things that those restrictive practices can lead to."

WA Advocate, October 2020 Zoom workshop with DRC

"...based on the fact that a lot of these restrictive practices occur in settings in which we don't have access, I'm only seeing the tip of the iceberg. That's part of the problem."

NSW Advocate, March 2021 Zoom workshop with DRC

"...there's no oversight beyond the people who are there. So if they are the people who believe that that is an appropriate way to be treating people, then those are the only people who are going to see that behaviour or that restrictive practice.

...many restrictive practices isolate people and isolation increases the risk of people not being able to report. Who can they report it to? The only people they're seeing are people using restrictive practices."

WA Advocate, October 2020 Zoom workshop with DRC

"...what we have seen in terms of our experience is that restrictive practices are really used for "behaviour" and that ...is to do with 'well, we don't want to deal with this challenge' and it's a perceived challenge. And that challenge is something which has a label put in by an organisation rather than actually asking 'is this necessary?' and then if it is necessary, 'who is saying this is necessary?' And within that conversation is 'did that person with the disability have that open, frank discussion, you know, with that person who can actually diagnose and say you need this as a restrictive practice?'

So certainly, from our experience, I think it's very important to note that really people with a disability don't often have the power to voice what they want, and so it is others that are actually, you know, whether whoever they may be - the parents, carers, people in organisations - they are speaking on behalf of the person with a disability and perhaps are seeking, for whatever their own reasons are, these restrictive practices, and certainly, like I said, it's often that it's not necessary.

So I would question mark, I certainly question mark when it comes across my desk, who's actually making this decision, is this decision necessary. But yes, often we find those issues there.”

WA Advocate, October 2020 Zoom workshop with DRC

“...a 13-year-old child with autism was placed with adults with autism in a Community Residential Unit. The behaviours of the other residents caused the child to self-harm and to be violent towards workers and his family, which led the service provider to have him admitted to a mental health unit, where doctors, who didn't meet the client, prescribed PRN [prescription is taken as needed] sedation medication. The service provider now uses the sedation medication multiple times each day to control his violent behaviour, despite unequivocal evidence that the child does not need sedation medication if he is not co-located with other people with autism.”

VIC Advocate¹⁶⁹

“Some restrictive practices are subtle, and even not recognised as restrictive. Eg. one member of a household having his meals sizes restricted as others in the household are on special diets. Doors being locked, cupboards being locked, are all restrictive practices.”

VIC Advocate¹⁷⁰

“...with the restrictive practices I feel it's sometimes, it's quite quickly put into place. I sometimes feel that the support workers don't really take the time to get to know their client. So the behaviour has come, and I do believe they often come from a need that's been missing. Yes, they can't solve everything - but take the time to get to know your clients, and it could be anything. It could be a smell in the house, it could be a food. It's going to take a while, but really get to know your client, because if you can't, if you really get to know your client you will see the triggers and you will know how to divert that before it gets to that stage, as opposed to putting in new staff who are undertrained with that client where... having new staff could inflame the situation. So to have that consistency in there, with the same staff and not all staff record incidents when they happen. Unfortunately, that is the reality. They are so busy and whether they have the time to sit down and do the reports of whatever has happened? So you are not getting the whole picture. ...I get reports when incidents happen, and I have to ask 50,000 questions because I believe the report should be that I should be able to read that report, close my eyes and envision being in that room. What time things happen? What else was going on in the environment? Staff are not getting that to the behaviourist because these reports are kind of pointless when they are not putting that really important information in there. So I think staff need to be retrained in how to do a report. What

¹⁶⁹ DANA's 2015 Quality and Safeguards survey - Response from VIC Advocate

¹⁷⁰ DANA's 2015 Quality and Safeguards survey - Response from VIC Advocate

needs to be in there, the detail. Imagine you are trying to explain it to someone who is blind and deaf. You want to paint that picture for them, and they can't hear what's in the background. They can't see what's going on in the environment. Paint the picture. A lot of staff aren't doing that. You are only getting half the picture when you're trying to fix the problem.”

QLD Advocate¹⁷¹

“medication as behaviour control is over-used as first port of call by too many careless people. [Restrictive practices] ruin their health, cause more agitation when coming off the dose, is used as an excuse to justify control over others. Legislation increases its use and normalizes it, there are many cover ups of mistakes, RP replaces a more therapeutic trauma informed approach to help people calm down or work their problems or anger out”

QLD Advocate¹⁷²

Group homes are more likely to use RP [Restrictive Practices] as a simple method of controlling challenging behaviours, rather than examining the underlying cause of the behaviour. I believe there is probably also an unknown cohort of adults with an intellectual disability that live with their (now elderly) parents who have been subject to unregulated long term chemical restraint. Before the NDIS QSC, using fixed dose chemical restraint during respite services in QLD only required the permission of the guardian. Older people with intellectual disability were not provided with the sort of capacity building when they were young that is now available. They may have unknown sensory issues that have caused challenging behaviours and never been addressed.

QLD Advocate¹⁷³

“People with a disability may be subject to long term chemical restraint. This can occur in both Group Homes and in Family settings (where parents who struggle to cope use chemical restraint in collaboration with the person's doctor). A person who does not suffer from a psychotic illness can be treated with drugs that further impair their ability to participate in society and their ability to speak up about abuse and neglect. In QLD, because there is a "skills deficit" exemption, long environmental restraints are common. There is no incentive under the QLD regime for providers to engage in capacity building to remove the skills deficit. This failure limits the persons access to the community and breaches their human rights.”

QLD Advocate¹⁷⁴

¹⁷¹ QLD Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

¹⁷² DANA's 2020 Restrictive Practices survey, Response from QLD Advocate

¹⁷³ DANA's 2020 Restrictive Practices survey, Response from QLD Advocate

¹⁷⁴ DANA's 2020 Restrictive Practices survey, Response from QLD Advocate

“...if you're a person with disability in an aged care facility, it's so easy... they slap on a restrictive practice like that.”

QLD Advocate, December 2020 Zoom workshop with DRC

“I think restrictive practices negatively impact people with disability and can reinforce the belief that the person is a permanent risk. Restrictive practices limit freedom and the ability to build independence. Restrictive practices can lead to serious mental health issues.”

VIC Advocate¹⁷⁵

“Use of unauthorised and authorised restrictive practice is common for people with intellectual disability. Where restrictive practices aren't used, it is common for people to think that it is a good way to solve a problem. Where RPs are not authorised, they creep in because people are often unsure of what constitutes a restrictive practice. It also appears difficult to have them reduced over time because people are not sure what to do next. Many service providers have difficulty having staff attend training with a Behaviour Support Practitioner because of funding, rostering and lack of commitment.

Many Behaviour Support Practitioners feel frustration that their BSPs [Behaviour Support Plans] are not being correctly implemented because of this issue. There are also many instances where staff/service providers and families are using unauthorised restrictive practices because they don't know what else to do, and they do not possess the resources or knowledge to do better. Many service providers also impose additional restrictions based on staffing and what works best for the organisation.

This is especially true for people subject to Supervised Treatment Orders (STOs) under the Disability Act 2006 (Vic). As it is a very small cohort, there is little scrutiny or oversight of the restrictions, and the service providers are able to restrict people in addition to the restrictions imposed by the order and treatment plan, as most service providers do not want involvement with this cohort. DHHS [Department of Health and Human Services (Vic)] have been beholden to service providers who manage STOs for years.

Restrictive practices, including chemical restraint, environmental and physical restraint, are routinely used in the prison system for people with intellectual disability. It is authorised as it falls under non disability legislation. There are no safeguarding mechanisms for people with intellectual disability in prison and Victoria is not OPCAT [United Nation's Optional Protocol to the Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment] ready/prepared to ensure that people with intellectual disability are no longer subject to torture (largely in the form of solitary confinement) in prison.

¹⁷⁵ DANA's 2020 Restrictive Practices survey, Response from VIC Advocate

This use of restrictive practices in prison that are usually labelled 'management', highlight that people with intellectual disability do not take their human rights with them as human subjects, they are bestowed (limited) rights (such as right to be free from torture) by the systems they are subject to. In many cases, they are subject to systems that do not have a rights framework or culture, and they are not afforded additional rights above those of other prisoners, despite coming to prison with little adjustment made to ensure equality.”

VIC Advocate¹⁷⁶

“There also appears to be limited motivation on the part of service providers to support clients to make complaints about restrictive practices, as they often appear fearful of losing the client's funding, or upsetting others in the client's care team. There is an enormous amount of negation of responsibility that appears to be driven by funding insecurity. Because there are so many people now working in the disability sector who are new and unfamiliar with RPs [restrictive practices], there is extremely limited knowledge about what constitutes RP. Many newer people to the sector acknowledge that it is an area they do not understand, and yet they work with clients who are subject to RPs. People who have had involvement in the criminal justice system are often very restricted when they are in the community, and that restriction is often supported by assumptions about the nature of their offending and what they are likely to do in future.

I had an advocacy client whose service provider asked him to sign an 'agreement' about restrictions. The restrictions included limitations on time in the community, not looking at or having contact with adult women in the community and not talking to people in public. When he signed that agreement, he had been charged with possession of child pornography. He at no point posed danger to adult women. Because he agreed to restriction, he was eventually chastised for smoking too frequently, using offensive language in his own home, told he couldn't practice two religions at the same time and viewed poorly for having a sexual relationship with another adult in his own home. This client made a complaint to his service provider which was upheld, and one staff member was no longer able to have contact with him. However, he chose not to make a complaint to the QSC because he was not able to understand who they were and what the point would be in doing it. He also felt very angry with NDIA at that time and could not understand that the QSC were a separate entity (and really, how reasonable is it to expect people to understand that when they look exactly like the NDIA?).”

VIC Advocate¹⁷⁷

“...[restrictive practices] limits access to other people, and so many people that we're aware of are restricted to institutions, including institutions of one, so the only people they get to see are paid support persons who may well be the people who might be abusing, exploiting or

¹⁷⁶ DANA's 2020 *Restrictive Practices* survey, Response from VIC Advocate

¹⁷⁷ DANA's 2020 *Restrictive Practices* survey, Response from VIC Advocate

neglecting them. And the other issue ...is the use of medications, which restrict capacity and ability for people to ask for or seek help... People are ascribed a very negative reputation through all of these kinds of things, including positive behaviour support plans, and ...these things being used as a first resort rather than a last resort. And when they're used as a first resort, then what they don't do and what we observe is they don't have actually good support plans, like ordinary support plans. How is it that you support a person around something that might be a behaviour of concern is sometimes just what it is, protest behaviour, it's protest behaviour about that you're living a shit life, you're not treated well, that you are excluded from the rest of the community, et cetera, et cetera, et cetera. And a lot of these... plans... are instituted very often in congregated settings and they're not implemented generally in the way that they ought to be. But again, it's around, we would see that people are protesting at what their living conditions and arrangements are, and that the support in those kinds of places, SILs, supported accommodation services group homes are driven by rosters, not by the individual needs of people. So we can't expect people to behave in ordinary ways when we put them into settings that are not ordinary.”

SA Advocate, December 2020 Zoom workshop with DRC

“One of the things that I've seen is the use of ...medication and used inappropriately and I have examples of this with people that we support. And these [psychotropic] medications were given at a younger age, and have never been reviewed and when you ask for a review, it's like, ‘Well, why would you do that, this is what's been needed and required.’

I have one case in particular where we did ask for a review ...and it took numerous meetings with a multi panel of people to actually have that person's rights adhered to, to actually ask for a review. And when we did get a review by a psychiatrist, the psychiatrist couldn't believe that the person was actually on the medication, it was inappropriate. It wasn't even related to what the person needed. It was just a form of restraint.”

SA Advocate, December 2020 Zoom workshop with DRC

“...in group homes, people are under restrictive practices and don't realise they are actually [restrictive practices]. Sometimes the support people, the staff in the organisation, don't even know what they're doing is restrictive practices. I haven't had anything from the senior practitioner, but I know that 18 months ago, I asked the state of Tasmania for how many authorised restrictive practices, and for all of the state, 18 months ago, it was eight... I'm talking 18 months ago, I don't know now. I was stunned, I was absolutely stunned that only eight...”

TAS Advocate, November 2020 Zoom workshop with DRC

"I would say probably the majority of the clients , the participants, I have worked with have had a restriction in some way or another. I actually flagged yesterday something about chemical restraints. Someone had said something about 'oh, we need a behaviour support plan for this participant because of their chemical restraints.' This person is nonverbal, confined to a wheelchair and it's like why would they be on a chemical, no behavioural issues, and the support organisation is asking for a behaviour plan for chemical restraints. And I'm like 'so are they actually on this medication because of chemical restraint or is it because of seizures or is it because of behaviours.' I just said, 'Well, I want to know why and what they're on, why you're warranting that.'

I think chemical restraint is a big thing that organisations and service providers don't understand, especially in Tasmania, because they haven't had chemical restraints I guess under the restrictive practices. Even locking fridges and saying to people, "No, you can't have that food" or locking away items, special items - I find that a lot of support workers still, even with the change with the quality and safeguarding coming in place, still don't understand what a restrictive practice is."

TAS Advocate, November 2020 Zoom workshop with DRC

"I think there needs to be a real pushback too, to make sure that there's evidence of many other things being trialled before jumping straight into a restrictive practice, because in my experience it seems like it's almost the go-to, and so long as you've got the paperwork, that makes it okay. But we know that then it increases sometimes in people more behaviours, more feelings of isolation, more behaviours. So I think there needs to be more extensive evidence of what's been done prior and really having that as a last resort."

TAS Advocate, November 2020 Zoom workshop with DRC

"...if you're talking about people in group homes, or other circumstances where they are effectively under the control of a service provider, you'd be heading towards 100%. The more the person's living circumstances are part of the community and are determined by the person and their close family and friends, you start to move way down, and you start to approach zero, but the more service providers have control of the person's life, the higher it is."

VIC Advocate, February 2021 Zoom workshop with DRC

"I feel that a lot of it is around lack of training and lack of insight and lack of attitude, and just thinking that a pill is going to fix everything, and that locking everything is going to be great, and 'we're going to get no behaviours'. So it's very frustrating."

VIC Advocate, February 2021 Zoom workshop with DRC

“What used to happen previously was there used to be some training allocated within the service provision, especially within the homes, the supported homes. So there used to be funding from DHS to enable some extra training to be done for teams and then the teams would go away and they'd start recording and they'd start working together. But from a conversation that I had only a few days ago is that, with a service provider is that, well, we don't have the funding to do that anymore. It has to come out of the NDIS plan. So if that person doesn't have enough funding, then sorry, but you can't get a behavioural specialist, you can't get extra training, because that's not allocated to that person.

So it seems to have gone backwards because it's all about money and it's all about... just from just knowing, working in the sector for a really long time, it seems to have gone backwards in that it's almost like I call it a babysitting service, especially in the group homes. That it's just there for a job and then they're just there to supervise and there doesn't seem to be a collaborative approach by the teams to actually want to know why that person is behaving the way they are, to actually really figure it out and work with the behavioural specialist and really get to know... They seem to just say 'let's go to the doctor's and let's get a pill to pop.' ...I guess it goes down to funding and the way that the system is set up. It seems to be very siloed now.”

VIC Advocate, February 2021 Zoom workshop with DRC

“...with mental health and autism, and that intersection of those disabilities and restrictive practices in regards to the medications... People don't realize that they're restrictive practices - they're just, that it's once again, it's “calming the behaviour”, and so that's why they're used. I just think it's a matter of education. I think, also, there's a culture because it's been so longstanding to choose particular medications to sedate people, in a mental health crises or similar, such that it's become normalised and so [we need] education around that there are other ways.”

ACT Advocate, October 2020 Zoom workshop with DRC

“Like the chemical restraint, they think it's normal, they are told by the managers it's normal, and they're too scared to say anything in care in case there's retribution against their loved one. ... It was one of the hospitals, one of the nurses rang us up and said, someone rang us up and said, do you know this person who has cognitive impairment is being belted to a chair so he doesn't wander because the nurses are too busy? You know this is, you know, and they probably thought that's OK. 'Look, we don't have time. The ward's really busy, this person is wandering around and we can't constantly babysit them.' No, you can't and you know they had to be educated that this was not acceptable. You can't belt someone to a chair. Yeah. So they don't even know.”

ACT Advocate, October 2020 Zoom workshop with DRC

“The issue of psychotropics is really problematic because they're used commonly, certainly in assisted boarding houses here in New South Wales, and they're used a lot in group homes as well and, of course, it's always, almost always under the guise of mental illness... I will quickly talk about the assisted boarding houses. You have a situation there where almost everybody is on some form of psychotropic, in the main, mostly [Quetiapine], which is a fairly toxic medication. Many of them aren't getting the sort of regular clinical review they should be getting. In many cases, the so-called positive symptoms of their so-called psychotic illness have long passed because they're in their 50s and 60s and so the need for that medication is questionable. And then they have a whole truckload of toxic side effects which accumulate and actually lead to all sorts of health problems. So we see that as a really significant problem that certainly the DRC would need to be addressing. And that you can mirror that in other states and territories as well.”

NSW Advocate, March 2021 Zoom workshop with DRC

Culturally and linguistically diverse people

“I think from... culturally and linguistically diverse people with a disability... the impact [restrictive practices] creates is fear and with fear you have so many other things that also degrades their living ... And one of the things is feeling defeated, feeling rejected, isolated, and to that effect you find a person under this restrictive behaviour will not participate and that means they are denied choice and control of their life.”

“I think it's because of the historical background... and if someone is coming from refugee and, you know, migrant communities, one of the things that they find is that there is fear of authority. And if they're under these restrictive conditions, they feel that they cannot say, you know, they cannot ... there's that feeling of guilt and it's very true there is an aspect of shame in the way they're treated or that kind of thing. So they feel through that way they will not be able to participate, even getting services, you know, under that kind of condition.

So it's a combination of multifaceted, a combination of things that happens to that person's life, which should be really considered. If you consider that the person is feeling... the person will open up and if you find... they're treated, you know, differently than what is their expectation, then they end up becoming more reserved and more feeling indifferent.”

WA Advocate, October 2020 Zoom workshop with DRC

“With the culturally and linguistically diverse community, we've had ... somebody who needed a behavioural support plan to be put in place for them for the training... There wasn't enough funding in the NDIS plan for that detailed report to be written and then when we asked for the report, the plan, funding for the plan to be translated so that the family could understand

what was written, there was no funding available for that. So with a child with a behavioural support plan that the family couldn't understand was a real problem."

QLD Advocate, December 2020 Zoom workshop with DRC

"In our experience... a lot of people we're working with, the service providers are not providing interpreters. Even people who do have NDIS, the NDIS participants, they don't have access to free interpreters. Services are not providing interpreters and I heard very often then people say, "I tried to communicate with him". How? How do you try to communicate if you don't speak the language and the person does not understand the English and cannot provide interpreters?"

QLD Advocate, December 2020 Zoom workshop with DRC

First Nations people

One advocate raised that the lack of cultural consideration in behaviour support plans can undermine their efficacy, and reflects failures to incorporate the values, perspectives and needs of First Nations communities:

"...often there's a really good plan and it works well when the client is in town getting respite, but when they're home again, the family don't implement that plan because it's not culturally appropriate. It's not manageable for them, it's not the way that they would normally interact. So it kind of, unless you've got consistency, those behaviour plans are very difficult to implement and to get that really good outcome of the participant understanding what the expectation is."

"I think the challenges almost go back to child rearing practices, where people learn through doing. Traditional Aboriginal people, it's not about setting boundaries, it's about allowing people to do things and make mistakes and learn. So, it's not seen as putting loads and loads of boundaries in place to keep people safe, it is not the way people operate out in communities. It's about you learn from watching how other people behave, you learn from doing things and making mistakes. You don't learn necessarily from your parents saying, "this is the rule".

And there are issues around gender relationships, so women - older women - cannot necessarily tell their younger sons with disabilities what to do. That's not seen as appropriate. Often, it's men who set the rules for men and because men die younger, a lot of those young men out there don't have a lot of fathers or uncles or people around to help them understand the expectations. If they have a significant cognitive disability, they don't go through men's business necessarily, and again, men's business is another way of men setting the example for men about how men are supposed to behave. But there is a lack of senior men around doing the right thing and showing young men how to behave.

And if you use substances, or if you have an alcohol abuse problem, and you might be, as a result of that, more likely to engage in behaviour which is exploitive of others so that you can get the resources you need to access whatever you're addicted to - yeah, there's a whole lot of reasons why it is very, very hard for those senior women to manage, particularly younger men who have cognitive impairment, maybe ongoing petrol sniffing or using gunja, marijuana, regularly."

NT Advocate, November 2020 Zoom workshop with DRC

Children and young people with disability

"There's been lots of other examples where children on the autism spectrum with complex, challenging behaviours are put in locked rooms, separate rooms from the other kids, or they're restricted from school completely, because their behaviours are so complex and challenging. Bus companies won't take them on the bus anymore and some parents have been forced to relinquish, even though they've got money, NDIS money to support their children, they are still relinquishing into state care because they can't... The respite facilities that are around, there is not enough training within the respite facilities or places available to put young people with complex, challenging behaviours into the respite facilities that are available because they're all full. In fact, I know of three in Melbourne that are already full of people, children, who have been relinquished. The NDIS was supposed to stop relinquishment but, although parents have got money and funding for short-term, overnight accommodation, which is a euphemism for respite, trying to find somewhere to put their child to have a break is almost impossible."

VIC Advocate, February 2021 Zoom workshop with DRC

"...the carers, often see it as a punitive measure, as if they haven't been doing the right thing. So, therefore, restrictive practices now have to be put in place. Everything that they have been doing in the past to manage - pretty much 'crisis management' for lack of a better word - must be put on hold because it's, in a way, seen as 'illegal' and wrong. So what's left for them to do? It's almost like they've been put into a position where they will lose carers who are no longer able to provide the care they were doing because of these restrictive practices rules. And without themselves being informed, "What do I do next? How do I fix this situation?" they are then looking at the NDIS to say, "Well, I need help". But the NDIS is saying, "I'm going to put a hold on everything because you need to do X, Y and Z" but there is just not enough communication to facilitate that, and for that to happen in a timely manner. There's always weeks and months of delay just for an understanding of what's happening to happen, let alone the actual implementation of restrictive practices."

NSW Advocate, March 2021 Zoom workshop with DRC

“...I have only just touched the tip of the iceberg in seeing some of this stuff and it's partly I think because of access issues and getting into places but also probably because I work in a general way. I certainly have seen a lot around recently - not a lot, but I'm starting to see more people telling stories around issues around medication, so for behavioural control. So experiences in the mental health system of being zombified through medication, that is really... it's been stated that it's for their treatment, not for behavioural reasons actually. But this is sort of creating this stupefying effect that leads to things like people telling me experiences of being sexually assaulted and not being able to, or harassed and not being able to respond because of the medication. ...So medication certainly seems to be... and things like anti psychotic medication... being not just used for behavioural control, but treatment, but then creating further avenues for other forms of violence and abuse. And things then also being discredited and not believed after making complaints because the medication then prevents people from having proper memory recall and things like that. So the abuse being perpetrated and then being disbelieved through the complaints or reporting process because of that. So that is certainly coming up.

It comes across in all the work restrictive practices across so much of what we do... certainly things in like boarding houses where, again, medication has been used. Seeing people kind of sitting around and not being able to go anywhere, not because they're locked in or chained up but because they've been medicated to the point that they're kind of zombified and can't move and go anywhere. Things like we have seen in the Aged Care Royal Commission, the use of Clozapine and other medications, things like that. And examples in group homes where people have been locked in and not being able to kind of leave. That's not something I am hugely familiar with. It has come up in some of my client work, though.”

NSW Advocate, March 2021 Zoom workshop with DRC

Lack of human rights

“A service provider will take over from another service provider and their attitude will be more cost focused, and the particular individual that they're working with has a lot more needs than they want to deal with. And so their attitude is well, we're just not going to put in the effort, I guess, to deal with that person and we're going to move them on and find a more easy person to deal with in this setting.

So the particular example I'm thinking of is someone who's been in a particular group home for a number of years, a new service provider comes in, finds that they aren't managing this person's needs very well and this person is behaving in a way to try to communicate that and it's just too much trouble. They evict them, and that's where the financial considerations of an organisation butt up against that individual human rights person-centred goal that we would like to see organisations pursuing.”

WA Advocate, October 2020 Zoom workshop with DRC

"...last year, during COVID restrictions, what I saw was that a person that I've already seen restricted, you know, unnecessarily, was put on the restrictions that no other citizen in this town that I'm situated in was put under. So there was certainly a huge gap and an infringement of human rights, you know, during COVID, for this particular person, because the person lives in a group home."

VIC Advocate, February 2021 Zoom workshop with DRC

There was one incident up here last year and this one lady ended up naked and in the river. It's just ridiculous. So they need to be more accountable, but also putting better safeguards for people with disability. And there needs to be more choice and control because, when I'm hearing people have come to us for advocacy and said, "This provider is not listening to me, I've said I want to work with this key worker so many days and they've told me no, sorry, you can't have them." It's like they're not available, but they are. The person with disability knows that they are. So there's that sort of discrimination as well.

NSW Advocate, April 2021 Solutions focused workshop with DRC

Theme - Profit-driven services

Advocates often drew attention to the market context of disability services underlying the lack of investment in training staff, increasing casualisation of workers and the imbalance of power between the service provider and the person with disability. People with high and complex needs are at a particular disadvantage, and many advocates report neglect, evictions or refusal of supports.

"...in some cases it comes down to that cost/profit mentality of...it's a business, we need to make money, so we don't have the money to... we're casualising our workforce, we're not investing in training, we're not investing in the support and supervision of our staff, so we're not equipping them with the tools to respond to those needs of a person in a way that isn't restrictive, or isn't violent, or abusive, or exploitive."

WA Advocate, October 2020 Zoom workshop with DRC

"...it's just that with the NDIS ...it's to do with that consumer approach, so the choice and control we've talked about for the participant. But when we look to the other side of the coin and we look at the service provider, their modelling is then as a business approach. 'We've got KPIs, we've got profit margins, we need to have streamlining of operations.' So when you get that sort of modelling, that goes to some level of conflict with the caring, compassionate - let's deal with these issues.

So it ...becomes a challenge for the participants and for the whole system to really work with. ...I think there's an imbalance between the participant and the provider and that leads to...you

know, if it's a little bit too hard, 'we can't deal with it, let's go to somebody else because that meets our KPIs and profitability margins.'"

WA Advocate, October 2020 Zoom workshop with DRC

[People falling through the gaps...] "happens because sadly, most people with profound and/or multiple disabilities are being supported under a business model, where providers ensure they are obtaining funding, and the person is seen as a commodity. I have seen services choose easy clients instead of "difficult" clients to ensure greater business prosperity. I have seen services choose to ignore harms occurred in homes by families to people with a disability because the service wishes to ensure funding continues to their service."

VIC Advocate¹⁷⁸

"...there are a lot of pressures on the system. I know there are a lot of former state-run... in NSW, the large providers got their share of the previously state-operated group homes. And some of the less-than-honest ones have gone about evicting less profitable clients. And so the only services that will accept them for supported accommodation are the ones that are new and run on a much thinner model of staffing, a lot lower level of expertise and skills in staff.

So you've actually got those market pressures operating in terms of the quality of care and things like that as well. So that is putting downward pressures on the cost for NDIS, and again it is stripping out those... unquantified kind of protections. You might have someone move from a service where there are workers who know their informal communication style, out to a new start-up service that runs entirely on agency staff, who don't know the person ..."

NSW Advocate¹⁷⁹

"I think training is available. The senior practitioners have always said we'll go out to group homes and do the training, and stuff like that, with the staff, but it's just the organisations, I guess, under the NDIS, getting all the staff together and 'how do you pay the staff?'

We're in a business model now. Everyone thinks about the money. So the NDIS don't pay for training for staff and stuff like that for staff meetings and stuff.

So I just think it all comes down to, you know, it's out there and I think it's always been out there. It's just it doesn't get fed back to the support workers. It goes to management, but the

¹⁷⁸ DANA's 2020 *Safeguarding rights and wellbeing* survey - Response from VIC Advocate

¹⁷⁹ NSW Advocate, "Advocates Zoom In On... *Advocacy & Abuse Prevention*", December 2020 Zoom discussion

training doesn't actually go down to the people that are actually doing the on-the-ground work”.

TAS Advocate, November 2020 Zoom workshop with DRC

“...I would say that if anything [the NDIS has] brought more “sharks out into the water”. The way so many providers are gouging the system, gouging plans, gouging through the portal, and yet the scrutiny and the hoops that participants have to jump through is obscene.”

QLD Advocate, December 2020 Zoom workshop with DRC

“...tick and flick and leave is the norm. No real investigation done in any service as this would upset the money-making.”

VIC Family member of a person with disability¹⁸⁰

Theme – Segregation and isolation

Advocates described the incredible vulnerability and isolation created by segregated settings:

“Attending a day program, living in a group home or being a part of any segregated setting should be a choice alongside many other options - however for many people there really isn't many other options out there, which is a real issue as there is no real choice for these people.”

VIC Advocate, February 2021 Zoom workshop with DRC

“Evidence suggests those most vulnerable to abuse and neglect are those who are surrounded by paid supports 24/7, and that having other responsible adults involved in their lives, provides for strong safeguards against abuse and neglect. Many people with disabilities are abused and neglected in care because no-one from 'the outside' is ever present in their lives to bear witness and take action.”

VIC Advocate¹⁸¹

“...I do know of a few services, in particular, that have sort of grown really quickly, but also while they say that they actively discourage other services coming in to group homes to provide day service. So for somebody who perhaps needs the infrastructure of their home, it means that they don't have another organisation coming in and being a witness to how things are for them within the home. So there's some sort of structural barriers there.

¹⁸⁰ DANA's 2015, *Quality and Safeguarding* survey. VIC Family member of a person with disability

¹⁸¹ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

And I've also seen big services that provide whole-of-life [services] not consulting with families around the way that they provide service,, and have made applications for restrictive practices without informing families even though they've been nominees.”

TAS Advocate, November 2020 Zoom workshop with DRC

“I think in some areas this is... this has improved under NDIS. Having access to funding that allows people to determine what they want to do and to have more individualised arrangements certainly has helped some.

I am sitting here at my front window, next door is a café, and about four doors down there is a disability service provider, and more and more I see the groups leaving that building are smaller. A person or two in the cafe next door will be somebody that others stop for a chat with. 20 people with a disability sitting around a table is a group that people will avoid. So the more you are getting people out in much smaller groups or with just another person, the more they're actually interacting with the community, the more they are known by the community, the more the community is accustomed to seeing them around and considers them part of that community. There's a couple of people that live locally that I see in the shops and they're chatting to everybody because everybody sees them around and knows who they are.

The settings that are completely segregated, and are going out in large groups, are doing the same activities as forever, they're going bowling still. I don't understand how that hasn't changed. I think a lot of their clients don't know that they can ask for it to change. They've done the same thing for so long. And those are also the environments where we get people reporting abuse because it's separate, it seems like different rules apply, it seems like it's not what you would assume anywhere else in the community, and things go wrong.”

VIC Advocate, February 2021 Zoom workshop with DRC

“...part of the issue with segregation is the differentiation that it creates, employee - person with disability and there's this hard line between the two categories of people, which in any other place doesn't exist. I can be an employee one place, and a customer of another place. I can be a co-resident. That blurring of boundaries is what actually allows people to get a better understanding of us all having the same rights...

And that, I think, leads into...about accessing closed environments, because the people who need to be accessing those environments, advocates, are important but self advocates are even more important. They see the things we don't see and know what they mean. They see the micro aggressions, they see the closed door. They understand the context in a way that somebody who has never lived or worked or spent significant time in such a setting does understand it. We need to be breaking down the barriers between who is a trusted person and who is some charitable object of a service provider, and see people with disabilities as

having useful and valuable experience. That they should be able to be paid to provide to others, and get out in the community, and do that. Stop segregating, full stop."

VIC Advocate, February 2021 Zoom workshop with DRC

I don't really understand why we still force people into day programs, which is sort of, you know, essentially like babysitting, and we don't allow people choice to do other activities in the community. And if people want to do a day program like thing, where they want to go somewhere, like to a community centre and do activities, then, you know, go for your life. But why we're still forcing this kind of, you know, segregated... this segregation, I find absolutely mind boggling. And some of the stuff that you see in day programs, just the meaninglessness of it, and the fact that the staff aren't resourced, and the staff are basically just getting through.

So I went to a day program a couple of years ago for a client who had enormous behaviours of concern, and there were huge problems with toileting, hygiene, all sorts of stuff, him hitting people, anger. And then, when I got there, the guy was sitting in the carpark in the rain. And I said to the staff, "Why is he there?" And they said, "He likes it there" and I kind of said, "You're telling me that somebody likes to come to a day program and sit in the carpark in the rain?" And they said, "Yeah, he always does it."

And just that, kind of, you know, like this is a man who wants to go home or go anywhere but not be in this place. And nobody was able to recognise that because it was framed as, "He's a really difficult client, we need more resources to control him", not actually, "My God, we need to get this guy out of here, he obviously hates it."

And that's one of the things that really concerns me - that kind of links restrictive practices with segregation - is that we look at people and we go 'well, in this setting they behave in a way that we consider to be really bad' and we don't recognise that what they're telling us is actually "this place is really horrible and I hate it". We look at it and go "well, he hits the staff, therefore maybe we'll take him to a psychiatrist and try to get him on something to control that, maybe we'll get him on an antipsychotic to try to control that behaviour, you know, we'll get a BSP [behavioural support plan] to try to get some strategies for managing that behaviour", without listening to the very human person saying, "I hate this crap". I just find any kind of segregation where the person doesn't make a choice to be with people, I just find absolutely mind boggling in 2020.

VIC Advocate, February 2021 Zoom workshop with DRC

"Strangely enough, ADEs [Australian Disability Enterprises] and day programs turn up to NDIS planning meetings to tell planners how much the client loves it. Why? Because they have been doing the same thing for 20 years, therefore they must love it!"

VIC Advocate, February 2021 Zoom workshop with DRC

“...people learn that if they are to misbehave in the eyes of people who are using these restrictive practices, they will be further restricted. So it becomes a cycle where the restrictive practice increases the use of restrictive practice, and that increases the isolation and increases the chance that that person won't be able to talk to anyone about it.”

WA Advocate, October 2020 Zoom workshop with DRC

“There's no way for third parties to come in and provide them with the information they might need to know - one, what they're experiencing is a restrictive practice; two, whether or not it's been put in place following proper procedures, and three, to who and how do they complain if they're unhappy with what's happening to them - They may not have access to the house without the people who are putting the restrictive practice in place. They might not have access to a phone, computer, whatever it might be that they need to actually reach out and ask for help.”

WA Advocate, October 2020 Zoom workshop with DRC

“...the value of the client's input/opinion is actively undermined. ...Violence causes a vulnerability to more violence. Segregation is violence because it isolates and controls people.”

QLD Advocate¹⁸²

“Stop using segregated settings, and follow international models of individualized true community-based settings which have been shown to reduce abuse and neglect and restrictive practice use.”

VIC Advocate, February 2021 Zoom workshop with DRC

“There are some new models of operating that have been developed but, by and large, for many of the traditional-style day programs that I am exposed to, many of them, a large percentage of them, I would say, are not better. They are still highly segregated and there's concern there, and a lack of access for advocates as well...”

NSW Advocate, March 2021 Zoom workshop with DRC

“That situation about every single service provider in that type of scenario is quite strapped and, as an advocate, when I'm in a situation where we're talking about group homes,

¹⁸² DANA's 2020 Segregated settings survey, Response from QLD Advocate

supported independent living, and yes, the NDIA is involved as well, my go-to has always been support coordinators to try to implement those things for an NDIS participant. But I just find that we all end up passing the buck because, like you said, the supported independent living providers, they're not there to case manage. They're there to ensure supports are put in place and that everything is in order with the property and the carers as such. A support coordinator just shows up at the very beginning of someone's plan and says, 'OK, you need X, Y and Z. Great, I'll check in with you maybe once or twice a year.'

And so advocates might get the referral but then our involvement is very limited because we're not funded to case manage. We're not funded to ensure that... there's no accountability when it comes to looking at the segregation that an individual is put in when they don't have an informal carer who would step up to speak up, an informal advocate who has the time and effort to actually bring the services to do what they're supposed to do. ...In a group home scenario or in independent livingno one is there to keep a support coordinator accountable, for example.

And without the knowledge of what is available out there, without someone suggesting to this individual "How about dinners every other night or how about take you to the library because you don't like being in a big group, you want to have that outdoor experience, but in a controlled environment." Without someone giving that suggestion, of course they're not going to ask for it. But who is responsible? Who will be accountable to do that for these individuals? Because otherwise they're left in that segregated setting indefinitely."

NSW Advocate, March 2021 Zoom workshop with DRC

"I have seen a day program consisting of clients just parked around a TV set. That is, secluded."

NSW Advocate, March 2021 Zoom workshop with DRC

"In my experience, people in group homes are encouraged to have no outside relationships. Visitors to a home are determined by organisation policy and schedules rather than by the people who live there. With limited external connections and tight regulation by organisations, there is little opportunity for abuse to be observed or reported on. There is little opportunity or support for people to make complaints about anything, particularly abuse, neglect, exploitation or violence."

NSW Advocate, March 2021 Zoom workshop with DRC

"One...angle is thinking of the problem from the view of a perpetrator, why do perpetrators feel safe and confident when they commit their crimes against people with disability, what is going through their minds and how can we make systems unsafe for perpetrators."

I'm just having a bit of... a little bit of research on the issue and the personal safety survey from the 2016 census. So it indicated women without disability in terms of sexual violence, 16%, which is pretty horrifying, 33% for women with disability. That's from the age of 15 onwards. And I would suggest that part of that is to do with settings and environments where perpetrators feel safe, like group homes.

Somebody mentioned congregate settings or secluded settings and the experience for people with disability of course can be absolutely horrific, not to mention neglect as well... that appalling case with that young woman in South Australia... So yeah, I mean, seclusion and segregation... these are the sorts of things where some of the worst things that can happen, like neglect to the point of people dying, sexual violence, and so on, we need to sort of dismantle these things, so perpetrators who abuse against people with disability don't feel as confident perhaps as they do in current settings...

...I guess sort of reiterating the point to start with, you have a grooming process often with sexual assault. Somebody in a group home, you know, employee who intends to abuse somebody, you know, a situation where they become sort of special friend, special deals and so on and that person, yeah, sort of feels that the perpetrator is really sort of looking after them, whereas in fact the perpetrator is working up to sexual assault.

I would suggest that if people were actually living in... and somebody mentioned this earlier... their own home rather than in this group setting, where they have no choice, real choice in the issue, that might be less conducive to forms of abuse... just to get away from this seclusion and this sort of segregation which, yeah, to me it just makes it easier for somebody who wants to do harm.”

NSW Advocate, April 2021 Solutions focused workshop with DRC

“Community rather than seclusion truly is a way of preventing abuse and neglect.”

NSW Advocate, April 2021 Solutions focused workshop with DRC

Theme – Attitudes and culture

Another recurring theme was the lack of cultural or attitudinal change from outdated attitudes towards people with disability that are dehumanising, disrespectful or paternalistic:

“One of the biggest factors we see between people in more problematic areas is the attitudes of the staff and the management working there, so when they see the people that they're working with as an individual, as a person, then we don't see as many problems.

When they see them as a problem, as a behaviour challenge, as a job, then that's where we see more restrictive practices, more abuse, more violence. And that is something that sometimes comes from the head down challenge of that organisation, that particular

organisation, and their views on the people they're working with and sometimes it's an individual."

WA Advocate, October 2020 Zoom workshop with DRC

"...but I still think there's a bit of a culture that people are treated like it's a chessboard and we need to move pawns around, or if somebody is disruptive here, we need to move that person there, and it might be a risk-averse decision. "Oh, let's have a look at who's in the house and whose parents might complain or who's going to be the most vocal, so let's move this person and these folk can't speak out, so let's pop this person in here". It's like a little roulette - it's like a little chessboard.

That was, I think, when DHHS [Department of Health and Human Services] had a number of houses, but you're seeing it potentially on a more micro level, particularly in Victoria with the six or so providers managing the housing. There's still this sense of 'we have a right to move people around wherever we like' because it's problematic and where's the consultation? So, again, it's cultural. This is someone's home. How dare you move just because you feel like it?"

VIC Advocate, February 2021 Zoom workshop with DRC

"I feel like we're going back the other way, where there's control and power and there isn't that - it isn't what it was meant to be. When I was working in houses, we were really striving towards that community participation. We were trying to sort of work with behaviours that were concerning, and we actually worked as a team within those facilities to be able to get things happening. But there seems to have been a really big shift, I reckon in the last even 10 or so years, that just seems to have gone back to that thought process around institutions, we're just here to supervise, and do no work."

VIC Advocate, February 2021 Zoom workshop with DRC

"Lack of choice and control. Behaviours of concern being used as an excuse to remove choice and control. I have personally heard many staff say they need to be seen as the dominant person or the person with a disability will take advantage of you."

VIC Advocate,¹⁸³

"The organisations think they know what's best for people, instead of consulting with other people as well. Like, I know I had an incident in the segregated setting with a family member and they said, 'Oh, we've changed worker because it was in the best interest of her to change that worker' and I'm like, 'Who are you to make that decision to say that that's in her best

¹⁸³ DANA's 2020 Segregated settings survey, Response from VIC Advocate

interest? You've had no consultation with her, and you've had no consultation with anybody else in relation to changing that.' But they just said, 'As an organisation, we think that's in her best interests'."

TAS Advocate, November 2020 Zoom workshop with DRC

"I have many clients in CRUs [community residential units], or have had, the NDIS rollout, and some of them were part of the early rollout, where in fact their life had deteriorated and the NDIA were saying at the start that with an NDIS plan, people's lives should improve. So I think, across the board in most cases the funding has changed, but they've still got the same support workers, they've still often got the same management structures and the same culture, the same approaches exist. And my main concern is that what that leads to is that they have preferred medical professionals that they use who will write a script for anything without question because they're being given, fed the information from support workers in some cases. While ever that can happen then,, certainly chemical restraint will continue and there's no accountability at all. And putting individuals with complex support needs, particularly with autism, with sensory issues a part of their everyday life, housing them together will lead to higher levels of restrictive practice."

VIC Advocate, February 2021 Zoom workshop with DRC

"...I've worked in disability for a number of years and I really think it varies. You know, different organisations have different cultures. So obviously as an advocate I see... there certainly is a culture [of using restrictive practices] in certain organisations and in this particular organisation, you know, it's not changing and it is a cultural issue I think."

VIC Advocate, February 2021 Zoom workshop with DRC

"...it's culture. There's a cohort, I think, of people that aren't even recognising that it's restrictive practice. Then there's people that are recognising it and might be too fearful to speak out. And then there are people who might be slightly detached and recognising it, and are very prepared to whistle blow or to connect with advocates or to find someone independent. And I'm sure there's a whole range of other folk in between that are covering the system. It's just not seen as being something that, I think people don't see it as worthy sometimes of connecting, or that it's in fact a breach of somebody's human rights. I'm just not convinced that people view it that way."

VIC Advocate, February 2021 Zoom workshop with DRC

"It's the people already engaged and interested and probably those practitioners that have some foundation, support and knowledge of people's rights that actually, probably attend it, the zero tolerance to abuse training."

It's about, we've talked about it, but it's about how do you do it systemically. But it's about changing cultures, it's about getting those that set the culture in organisations to be committed to things like zero tolerance to abuse. Is it reflected in every disability service provider's strategic plan? That would be interesting, wouldn't it, as a measure? Why doesn't the funding body set a benchmark around the percentage of people on restrictive practice, you know, those types of things that are not punitive, but they urge organisations to stand up and take notice of different ways of practising."

VIC Advocate, February 2021 Zoom workshop with DRC

"I was involved in the making of one of the series in the 'zero tolerance program', yet no worker at the I program I worked at was shown any of the videos that were produced."

VIC Advocate, February 2021 Zoom workshop with DRC

"I think for me a part of it is just the intrinsic value of people with disability, you know. I think that if we can address that right from the start."

VIC Advocate, February 2021 Zoom workshop with DRC

"...as someone that's worked in day program for about three and a half years, I think a huge issue in terms of trying to create a great culture, and also living out a good culture in practice as well, is there's really limitations on, kind of, high limitations on admin time. The manager always talked about how there was really limited funds for training and he'd jam six days worth of training into one day at the start of the year and so you'd never get any quality training. You were just kind of being force fed information, but in a way that wasn't quality - you weren't able to ask questions, you weren't able to really learn.

And also, you were expected to keep notes on important things that happened in the day. You were expected to make reports on anything that happened that was concerning or risky, but you were given little to no time to do that. And so that meant that people's supports were taken away for a while to do that, or it meant that it drove people to do things that made things quicker and easier for themselves because they didn't have time to do things properly.

And I guess, yeah, because I think there's lots of issues with culture as well, but there's also issues with resources which drive a problem in culture, because if you're not resourced to support someone properly, you're forced into a situation where you have to work out how to do your "job" in a way that just gets you through the day and then that forces a bad culture.

Yeah, so I would say in terms of day programs, see them as a segregated setting, see them as being underresourced, see them as having a real trouble of actually being able to provide something that's of quality to people when they have very little planning time and very little

resources and, yeah, being able to provide people proper support. And also, it is risky for abuse when you're underresourced."

VIC Advocate, February 2021 Zoom workshop with DRC

"...we talk about the philosophy and the attitude people have, and a good example recently of how bad this is, that you look at the Minister Roberts' conversation recently about disability and prostitution and how, I feel very disturbed personally, about his framing of that, and I will give you one example. We talk about the problem around sexual violence against women and girls with intellectual disability. I have had a client in the past who was seeking out a relationship as a result, was being sort of, it's a long story, but was seeking out stuff in social media and in the community and was getting abused by men and I won't go into the details of that, but it's just a good example where if you can't have a conversation with clients around, or with, the NDIS around relationships and people with disability actually being seen as human and wanting to have sexual relationships, and then have the Minister framing this as people with disability using their NDIS funding for 'prostitution', we've got a real problem on our hands. So I think that just showing some of the disgusting attitudes that we're battling against in this area, particularly, and how that relates to extreme levels of violence and potentially perpetuates it further."

NSW Advocate, March 2021 Zoom workshop with DRC

"very often human service workers and services are themselves institutionalised in their thinking."

SA Advocate, April 2021 Solutions focused workshop with DRC

"...we need to lift the bar in terms of expectations because the support worker... it seems that they've got more sense of responsibility to their employee than they do to their clients. So we need to somehow shift that, and in fact, to the community as well, because when I witnessed this issue of abuse, the local inspector who lives three doors up walked past, witnessed the same thing and did nothing. So there really is a need to lift the bar in terms of expectations and everybody's responsibility to protect the rights and prevent abuse."

TAS Advocate, April 2021 Solutions focused workshop with DRC

Topic – NDIS and Behaviour Supports

"...since the introduction of the NDIS and the quality safeguards, on a couple of occasions services don't actually understand what a behaviour of concern is, and they're seeking positive behaviour support plans to try to get, I guess, better training on how to do a particular issue. And in order to get that, they're using language that's quite harmful to a person's

reputation. They're bringing out past behaviours, and they are also describing things in a way that makes it sound like a behaviour of concern, but when you put it in context it isn't.

So a couple of examples of that is: someone I advocate for potentially has a tic and this person has done this particular involuntary movement for a long time and they're describing this tic as a behaviour of concern because it's becoming more apparent. And when I tried to challenge that it wasn't actually a behaviour of concern, it was just something the person did to communicate or was an involuntary movement, the NDIS still provided a positive behaviour support plan. And lots of the issues they raised in the interim support were ... the person was communicating when they had no other way of doing so.

And so another example was the person was trying to get out of a car at stopped traffic lights, but this person didn't understand ... because of their disability, they didn't understand they hadn't arrived at their destination but were stopped at a traffic light.

Those were the sorts of things when you put it in context, it's not a behaviour of concern, but that's what they got the positive behaviour support plan for. So while there's extra measures in place, the services are still inappropriately describing and referring people for those plans, when actually what they want is perhaps more training to deal with particular issues."

SA Advocate, December 2020 Zoom workshop with DRC

"...there's also the impact of the NDIS funding to implement some of those positive behaviour support plans in terms of having the correct amount of intervention by the specialists to be able to go in and provide training for direct support workers who are supposed to implement that plan."

QLD Advocate, December 2020 Zoom workshop with DRC

"There are issues with maintaining funding, I have worked with a couple of clients who had the amazing behavioural plans and 2:1 funding to ensure support. After 12 months, there have been no behavioural concerns, due to them being well supported. No incidents reported means the NDIS funding will be cut and then they are no longer able to be supported well enough."

VIC Advocate, February 2021 Zoom workshop with DRC

"A recent experience that I had for a young man who I am advocate for - He's now an adult but very recently turned 18 and has very significant behaviour support needs. He recently had his NDIS plan reviewed and, as part of that review process, during his 12 month plan, the family was requested to develop a behaviour support plan through a registered [behaviour support] clinician, and they undertook that process. Restrictive practices were, I guess,

highlighted as being undertaken with him by the clinician. The mother was outraged that the things that she does just to keep her son physically safe and alive, were being labelled as a restrictive practice, so there was work around, I guess, explaining that situation to her.

Now, this young man, his NDIS plan review meeting took place and we explained clearly to the planner that within 48 hours he was going to be completely without any level of funding. He was left for 15 days with zero dollars in his plan, so no ability to provide any supports, because they said that they had to take time to have the restrictive practices lodged and approved. Now, this is despite the fact that the mother had willingly taken part in having a really comprehensive [behaviour support] plan drawn up, had done everything right through every part of the process and had that done a month prior to the plan review meeting. And this young man was left with, as I said, no funding for 15 days, and the NDIS were very aware of that. In the end, I had to raise the issue repeatedly with the state manager, and they finally approved the plan 10 minutes past 5 on a Friday night after the mother had called me and said that she couldn't face going through the weekend without any overnight supports or support for her son."

NSW Advocate, March 2021 Zoom workshop with DRC

"I have [had dealings with NDIS Quality and Safeguards Commission], only in the instance of just trying to obtain information and to also speed up the delays involving funding approval for a behavioural support specialist to put together a behaviour support plan, and so the extensive time it takes for that plan to happen and the number of hours that the behavioural support specialist might need to put in until the restrictive practice is approved. It takes so much time... and I have tried to reach out to many different avenues to make that happen... And the response I receive is: 'It's been escalated to the relevant team', and that's it. 'We don't have any further information we can provide you, apart from we're looking at it. We're looking into it.'"

NSW Advocate, March 2021 Zoom workshop with DRC

"We have had request for advocacy support from a support coordinator. The participant is in shared accommodation. They don't have any family members or appointed guardians. There is a behavioural support intervention which is funded through NDIS and they need to have restrictive practices signed off. Who is going to do that? That's what the question is, and we've been asked for support on that. So that's something else to throw in the mix about restrictive practices and those practicalities about getting them signed off in the first instance."

NSW Advocate, March 2021 Zoom workshop with DRC

"I have just found that with a lot of behavioural specialists, registered ones, they're not always across restrictive practices. So I have found that those who are great with preparing a behavioural support plan, they will then have to do their own research or speak to their

managers or their team leaders in putting together the actual restrictive practice side of things. Often enough, part of the procedure, I believe, is they do need that two-person kind of check because it's part of the requirements. But I have just found, I just haven't really come across anyone who really understands the space really well, and that's a huge issue because there's hundreds and thousands of people, individuals, who might need it. But if there are only a small handful of specialists out there who actually understand, it falls back on advocates. I found myself in a situation where I am trying to pore over the legislation on restrictive practices. I am going through websites trying to work out as to who does this, and who does that, and who do I talk to get to this set up for this family. And when I finally find that person, for example, a behavioural specialist, or I'm speaking to the receptionist, they kind of go, "Oh, we don't do that". So what do we do now? That's the biggest obstacle I have come across."

NSW Advocate, March 2021 Zoom workshop with DRC

I have had quite a few examples where a client will have a BSP, a good behaviour support plan, and they have got quite complex needs and there's a lot of restrictive practices including in the BSP. And even though it is stated how they will be eliminated or reduced, there's absolutely no funding at all for implementation or training in the budget, in the NDIS budget, which is just ridiculous. And that does come up time and time again, and then restrictive practices are just used, and that plan is then essentially rendered useless.

NSW Advocate, March 2021 Zoom workshop with DRC

Topic – Accommodation

"An organisation doesn't view a group home as a home. It views it as a workplace."

NSW Advocate, March 2021 Zoom workshop with DRC

"People are still being placed in accommodation services rather than living in a home that reflects their needs, their wants, their personality, their preference.... Systems and services for this cohort are most responsive to the needs of paid workers, services and government, rather than the people themselves. Improvements in regard to design principles, accessible public transport and communication and information systems, are impotent when a person spends the majority of their life in a group home, boarding house, or other residential facility."

SA Advocate¹⁸⁴

"So segregated settings including group homes, particularly those that now come under SIL [Supported Independent Living], which then impacts on restrictive practices because what

¹⁸⁴ DANA's 2014 *Inclusive and Accessible Communities* survey, Response from SA Advocate

happens to one person in the household has to happen to all and the issues around this, is it about individuals or is it a financial issue of the service around what's happening?

We have a lot of interaction around hostels where people are prevented to have advocates if they're speaking to their advocates about their situation, or they're prevented from having access to the community if they're telling people in the community what's happening to them in the hostel. And also, these are people who have public guardians in place.

...the Safeguarding Commission in Queensland has been useless. They refuse to even participate in any complaint process if there are guardians involved, or even if there's an EPA [Enduring Power of Attorney], and the other issue for us is, that really segregated setting, of course, is nursing homes, where talk, talk, talk, but people are still there."

QLD Advocate, December 2020 Zoom workshop with DRC

"Accessible and appropriate housing is horribly under resourced. People with disabilities are waiting around 12 months on the "priority" housing list, when the typical wait expected is 3 months. They are waiting in totally inappropriate and sometimes dangerous conditions for extended periods of time. This is because there is not enough accessible housing, and also because people with disabilities do not have access to adequate supports to move from supported accommodation environments."

ACT Advocate¹⁸⁵

"...their way to address things that, that could end up being around abuse and exploitation, they get IVOs [personal safety intervention orders]. They get one person to take one out on the other and then that person has to leave, and there's a risk of homelessness then. That is the serious end, when an organisation tries to do something where it all seems good on the surface. We know that if these people are not having a variety of services come in, then if they don't have any verbal communication, how do they get to share that?"

VIC Advocate¹⁸⁶

"...if you are in a group home situation, if one person has restrictive practices, that could actually impact on the rest of the people in the home. And they are actually not required, they're not actually needing the restrictive practice, but because of the person - the individual needs - it actually impacts on the whole group. And that can have negative connotations I guess for other people and their access to other things."

SA Advocate, December 2020 Zoom workshop with DRC

¹⁸⁵ DANA's 2014 *Economic Security* survey, Response from ACT Advocate

¹⁸⁶ VIC Advocate, "Advocates Zoom In On... *Safeguarding rights and wellbeing*", December 2020 Zoom discussion

"...in terms of making complaints about the use of restrictive practice on an individual, I know from my own history working in supported accommodation there would be plenty of times that the individual doesn't understand that restrictive practice is being used, but also wouldn't have the capacity to complain about it either and it just kind of becomes, yeah, normalised... so they don't necessarily agree with what's going on, but they wouldn't have the capacity to kind of formally disagree with it either, without using maybe physical aggression or something like that."

SA Advocate, December 2020 Zoom workshop with DRC

"I just want to add around SRFs [Supported Residential Facilities] that we've been involved in - these are places where people are forced to live in the same room as another person. They are forced to eat the food that's given to them. So if you decide that you would prefer to cook your own meal, you can't because you're not allowed to use the kitchen. If you wanted to go out for dinner, you still have to pay, so the ones we're aware of it's a percentage of your income. So you're paying 83, 85% of your income and then you don't have any money left over to be able to go out and have a decent meal.

We know somebody who loves to cook and loves to go out and have lunch at their local hotel or whatever, and that person had to scrape money together every fortnight to be able to do that once every so often. And I think they are very appalling places, and they certainly affect people with intellectual disability, but also people with psychosocial disability who are forced into those kinds of environments. Lack of housing, lack of housing, lack of housing."

SA Advocate, December 2020 Zoom workshop with DRC

"...there's 45 people living together that have been there for a long time, and we haven't seen much change with the NDIS other than there's more staff than people, and people are even more overwhelmed by the amount of people living there. It's not a home. They've got nowhere to have a bit of space, absolutely nowhere. There's a lot of staff but people don't think people's lives have changed as far as decision making and where they want to live and what they can do.

I went to a plan review for somebody last month and they assume on the plan of that person, that that person was happy to stay there, and when I got involved planning with this person and asked him what he would like, his goals, what he told me is, "Get me out of this hole...." But it goes on his plan, because the service provider did it with him, he was happy to stay there.

We haven't witnessed much change in those settings with the NDIS, other than people being overwhelmed and more staff than they had before. It's fascinating to see hive of activities, and there's nowhere for people to go for a little bit of privacy."

TAS Advocate, November 2020 Zoom workshop with DRC

“...that segregated living issue. One of the things to do with affordable housing in Queensland, there's such a shortage of affordable housing and such long wait lists for people, that to try to get people housing where they can be supported to live on their own if they wish or with another person if they wish, is so difficult.”

QLD Advocate, December 2020 Zoom workshop with DRC

“We have been talking about the lack of appropriate housing for 20 plus years and nothing has changed.”

VIC Advocate, February 2021 Zoom workshop with DRC

“I think we're all very sensitive to the fact that...the availability of alternative accommodation, as opposed to group homes where often people just end up in living alongside people they don't want to live alongside that might trigger behaviours of concern, and so on, just the lack of availability of well-supported, independent living options, certainly, I think is a driver of very negative outcomes and people being victims of violence for sure.”

VIC Advocate, February 2021 Zoom workshop with DRC

“We recently had one of our clients who was evicted by a State Government housing authority, and the eviction notice said that it was temporary while the place was being refurbished, but there were no plans to refurbish it and he was being evicted and was going to be homeless. We had to use our powers under human rights and VCAT [Victorian Civil and Administrative Tribunal] to get that order taken out, that eviction notice taken, because under their own housing responsibilities, the state authority was supposed to provide him with temporary accommodation while they were rebuilding it. But they didn't have that, and they didn't put a date when he could come back. In effect they were making him homeless. We had to interfere with that.”

VIC Advocate, February 2021 Zoom workshop with DRC

“I think one of the issues that's concerning me, that I'm seeing with the rolling out of the NDIS and especially SDA [Specialist Disability Accommodation] and Robust Build, is that we're seeing a resistance from the NDIA to fund single dwelling options for people with complex needs that have capacity. So if they need 24 hours of care, there needs to be another room for support staff to use when they're on shift. There appears to be a pushback from that obviously - for I certainly had a discussion with somebody yesterday and the reason that they

were given was that it's not value for money if the person is supported, if they're the only one being supported. But the reality is that there are some SDA approvals coming through for single dwelling situations. So there needs to be consistency with that."

VIC Advocate, February 2021 Zoom workshop with DRC

"We have a number of people that we work alongside from an advocacy point of view that reside in SRSs [Supported Residential Services]. How do they come to us? It's very mixed, but often it's an external provider that might be raising a concern about the SRS. And again, it's a little bit of, it's about oversight. They're private proprietors. They can tend to operate by themselves, and they don't, sometimes they don't believe that they have to meet any particular requirements. So it's open to potential for abuse and neglect, and one of the biggest ones we've found as a bit of a trend, if you like, is financial exploitation. So people are certainly taking advantage of what's in front of them."

VIC Advocate, February 2021 Zoom workshop with DRC

"I have found that organisations are moving people across their various houses just to shuffle the client. So that they are moving to places where they think they won't be a problem or that they'll be less of a problem. So the solution is basically to - if they have a number of houses or accommodation places - they'll move them to where they might, where they think the problem will be minimised or swept under the carpet, or something of that nature. So I see that sort of fairly regularly."

VIC Advocate, February 2021 Zoom workshop with DRC

"It reminds me, sadly, of what's happened in the Catholic Church. They moved the perpetrator, the priest, around to another parish. If you're moving the perpetrator who's bullying or being abusive to another resident, you're just moving them around to another house. The problem is not solved that way. We need [there] to be intervention programs, you know, positive programs to assist that person. Just moving them around like a chess piece doesn't work."

VIC Advocate, February 2021 Zoom workshop with DRC

"...there's still very much a sense that people can be moved, and they shouldn't complain."

VIC Advocate, February 2021 Zoom workshop with DRC

"I've encountered this issue for some time, that the providers seem to be able to pick and choose who they want to provide services to and they look at the potential risk profile of the

client and potentially make decisions based on that - whether the person is suitable first of all to even come into their service, and then obviously then there's a question over which property or what are the potential risks, can we manage this person? It often seems easier just to say no rather than look at how can we support the person. So I've certainly worked with many clients who have been on this roundabout of even trying to find a place. NDIA have approved funding, so SDA [Specialist Disability Accommodation] funding has been approved, but just so many rejections from applications."

VIC Advocate, February 2021 Zoom workshop with DRC

"'Problematic' customers are being declined SDA [Specialist Disability Accommodation] places. People who have a high-risk profile have their SDA applications rejected again and again"

VIC Advocate, February 2021 Zoom workshop with DRC

"The biggest problem is getting the conflicts of rights in balance. Anywhere you've got a segregated setting, you've got the rights of the residents who live there versus the rights of the workers under OH&S laws to a safe workplace. And in almost every case that we get involved, the balance is tipped towards the worker, and that means segregating or some sort of abuse or neglect in relation to the client or the resident that lives there.

It's largely got a lot to do with insurance, WorkCover insurance, because they are very insistent on things like providing a safe workplace for employees. The trouble is that many of these segregated settings are also residences, they're people's homes, it's where they live, and their rights to come and go and do what they want in their own home are restricted because it's also a workplace. And OH&S ensures very, very strict [penalties] with service providers who don't put in the protections that make their workers are safe and this is always a problem, always. And every time you get a situation like that in our case, it's always tipped towards the balance of the workers."

VIC Advocate, February 2021 Zoom workshop with DRC

"There's one particular place in Melbourne who have always charged well above what people could afford... I don't know about in other places, but in Victoria SRSs [supported residential services] charge almost up to a person's full pension. So often there are lots of SRSs in Melbourne where you'll find the residents begging on the street close to the SRS because they can't afford cigarettes and the food is disgusting and that kind of thing.

That's not an uncommon thing, but there are SRSs now who are ...they're capturing clients so they provide all the services. They've opened up as support coordinators, they've registered with NDIS, nobody seems to be questioning their practices or anything. And there's one particular place in Melbourne who have always charged well above the usual rate

and either DHHS [Department of Health and Human Services Vic] or corrections have always paid to have clients with justice system involvement live there and that service provider has now, yeah, they do support coordination, they do everything now, and, yeah, they just capture clients and they, you know, some of the clients who live there are incredibly vulnerable and, you know, have had substance use issues.

And there's one man I know who lives in that place who it's really hard to even get him on the phone because whenever you ring up, they want to know who you are, why you're calling and they stay in the room when he's having a phone call. They're really suspicious of everything and they are very... he says to me, "Oh, my order finishes here and I want to move out, but they've told me I can't" and they control everything. They take him to every doctor's appointment, they tell him he can't go off certain medications he doesn't want to take. Everything is just controlled and they're making huge amounts of money doing this and the staff are... the facilities are still grotty, the food is terrible, the staff are minimally, if at all, qualified and they treat the residents quite poorly, but now those people, you know, there's nothing stopping them making huge amounts of money through NDIS."

VIC Advocate, February 2021 Zoom workshop with DRC

"I think often for the people who I'm providing advocacy for, it's a matter of physical safety. And it sounds dramatic, but for some of them, without the restrictive practice being at place, they would be at risk of being killed. So, in that instance, it's never even thought to review it or to look at a behaviour support plan. For the people that I support... living in supported accommodation, behaviour support plans seem to be a way of having any behaviour restrictive practice that they require authorised in perpetuity."

NSW Advocate, March 2021 Zoom workshop with DRC

"In many group homes, clients are living in the next room to an abuser. In many cases, having their own home with supports in place would mean they would not be vulnerable to such abuse."

NSW Advocate, March 2021 Zoom workshop with DRC

"Here in New South Wales, of course, we have fundamentally two different types of board housing settings - the assisted boarding houses, of which there are around 17. The number varies because some new places come on board and others close. There's, of course, the far, far bigger issue of the general boarding house sector - This matter is currently all up for review by the New South Wales State Government, so they're sort of looking towards the future of the boarding house sector and I'm sort of a bit silenced here because I'm on a committee where I can't really speak to some of the things I have heard there, but it does concern me that the NSW Government sees a future for the boarding house sector. It also

concerns me greatly that it seems - and I stand corrected - that the NDIS sees the future for the boarding house sector, which really gets away from what the CRPD [United Nations Convention on the Rights of Persons with Disabilities] says around people with disability, being able to live in the community and participate in the community. And I think it also says how entrenched these problems become, because this was a critical issue in terms of this sort of congregate living way back when Brian Burdekin did his Human Rights and Equal Opportunity Commission inquiry into mental health way back in the early 1990s. He specifically pointed to the problems of the rooming house sector, as it was called and still is called in Victoria, and he actually visited a place ...and was outraged and talked about the need to get away from this sort of institutional living, and I think that's the critical issue.

Is this the boarding house sector, for the people that want to talk about the future of that, they really need to do some basic research around the context of institutions and how they institutionalise everyone within. And certainly our experience in that space over, [our organisation's] experience over the past almost 20 years, has been basically that everyone within that setting is institutionalised and even now, you will get examples where people, of course, are supposed to get individualised support through the NDIS but things are basically then spread out across everybody in the residence. So everyone's doing the same activity. Everyone, as I said before, almost everyone, is on the same medication. There's not the choice of meals. So it's a really critical issue and everybody ultimately is complicit in keeping that whole thing running, and so you're not in effect seeing...

I'll give you an example, which is a case example. Trying to get someone to transition from an assisted boarding house back into the community is extremely, extremely challenging for us as an individual advocacy organisation because it's assumed that assisted boarding houses are the end of the road. Many of these people, for example, have been screened out of long-term stays in places like [local] Hospital... a terrible, terrible institution... and everyone's saying, "Well, this is it". Now, I have worked in various settings ... and when I was at [another organisation] we actually tried to bust out people from a particularly bad assisted boarding house, and we failed. And when I say we failed, it's because the whole system didn't support us doing that work. And that's even with the authority of government.

So it's a really deeply entrenched problem, and I would really compel the DRC to try and look at - start with looking at the research evidence around institutions. And there's a whole legacy of stuff in terms of research evidence going back to things like the Callan Park inquiry back in I think 1960, 1961. We know what these things do to people. I suppose in terms of, if we're going to look at this from a rights-based focus, we want to be looking forward to the future. How do we afford every citizen the right to participate and live in the community?"

NSW Advocate, March 2021 Zoom workshop with DRC

"...talking about the ABHs [Assisted Boarding Houses], I made a list of the some of the issues I have come across. So medication was huge. Severe malnutrition and illness. Concerns around sexual violence, where men and women were co-located, often in shared, not shared rooms, but there was still more than one person per room and easy access to different rooms.

People having things stolen. Not being able to ... we were told directly that we are not to encourage people to leave the boarding house. And to move into somewhere else, even if we did get someone out and maybe want to move them into social housing, that then brings up a whole lot of other issues, which is a separate conversation.

ABH providers becoming NDIS providers themselves and then double dipping, so ...potentially, but also having more control by... we heard one case of a provider getting everyone to cease their other service agreements and sign up with them as the NDIS provider. A lot of people being under trustee and guardian in these environments as well, so another layer of control in that environment. Having all their money controlled, also most of their DSP going to pay for boarding and lodging, and then very, very, very poor compliance or oversight mechanisms in those systems. So I just wanted to mention that was a list of just some of the stuff I had come across in those environments.”

NSW Advocate, March 2021 Zoom workshop with DRC

“...it seems to be that the assisted boarding house sector is under considerable pressure in terms of their business model, and so it's not actually working out perhaps the way that they thought it might in terms of the NDIS being some sort of cash cow. There's also an issue that not as many people are being screened in to assisted boarding houses as previously, so there's actually pressure there. There is a thing when people hit 65 in assisted boarding houses, so they no longer become, if you like, good for the business model, so there's pressure to move those people on, and I can give anecdotes of terrible situations where that's indeed happened. But, I think because this is all a subliminal phase here in New South Wales until the NSW Government sort of settles on where it's going, it does seem that the goal is to reinvigorate the sector. And I think, hearing people speak, what really concerns me is we're still... I mean, I've been doing this for decades. We're still having these conversations when... when it comes to people with disability doing basic things like going out the front door and choosing what they want to do with their day - that is something people with disability have to wait for. They have to be on the bloody pathway and wait until everybody else decides it's actually OK. And I think that really gets to that attitudinal stuff that underpins all of this stuff in terms of restrictive practices and other acts of violence perpetrated against people with disability.”

NSW Advocate, March 2021 Zoom workshop with DRC

“The NDIA is also telling a man with severe GAD [Generalised Anxiety Disorder] who requires 24/7 [support] that he will not get 24/7 without opening his personal home to a renter with disability to share his supports. He will have all the same problems as well. Most of the people I advocate for are in the very same problem housing...”

QLD Advocate, April 2021 Solutions focused workshop with DRC

"I have advocated for a client by just being with him at a Housing NSW office. He got respect and proper service just because someone else was present. It's sad in way but unfortunately that is so often the case."

NSW Advocate, April 2021 Solutions focused workshop with DRC

Institutionalised aesthetics

"I have had experience in... SRFs [Supported Residential Facilities]... I know some of our other advocates have had some contact with some people in that sort of segregated environment. What I have found is that the so-called caretakers, a couple of issues... the NDIS wasn't covering very much of their expenses while in those places. ...They were really struggling to get NDIS funding, suitable NDIS funding.

And the other thing is you can really see, the ones I've been in, the actual even just the aesthetics of the place is very run down, lacking in resources and people - it felt really institutionalised walking around with no purpose, the dining room situation was everybody ...again that it felt very institutionalised, everybody is just sitting, you've got your meals and you walked out. It didn't feel... if we're looking at ordinary life or what would be expected, I wouldn't want to be in one of those places.... Yes, it was very wanting."

SA Advocate, December 2020 Zoom workshop with DRC

I think there's been many... advances and improvements in terms of the architecture, the design aesthetics, we still need to focus from moving away, from the look and feel of a setting that is like a prison cell, and more to something that is what any person would expect and would enjoy, that really promotes healthy living from a physical and mental health perspective. And also, really promotes social interaction with the other residents of the place or people who come to visit, an ability to get around to be independent, to get outside. So we really need to ensure that to the greatest extent possible, all those standards continue to be achieved. Or improved upon.

...just to link it all back once again to education and capacity building of service providers - to understand about how design of where people live is really important. I think that that should be included and I just kind of reflect back when I was representing a group of family carers at a residential aged care facility in Canberra, because the management had created this dementia unit. And it was just, like, completely locked away, dark and I know what they were thinking. They were thinking 'they have dementia. They're not gonna notice' which was absolutely wrong. Of course, they're going to notice, and that's why people with cognitive impairment tend to - inverted brackets, inverted commas - ("wander"), like they move around. It's because they're really unsettled and unhappy. And it was really showing in the "behaviours". Not that, I don't want to use behaviours, but the way they were reacting to that

setting. So I think it's fundamental that the people that manage these different facilities are educated about what is needed.

ACT Advocate, October 2020 Zoom workshop with DRC

“...particularly about the architecture space, so I don't know how many people have gone to the high dependency unit and the adult mental health unit here in Canberra - But it is... like a jail cell and it has very disgusting, dirty linoleum on the floor. It is dark, there are no plants there, it's false grass on the floor. Now, while I understand most people are in the high dependency unit because of aggression, aggressive behaviours, it is not a therapeutic space. And neither is the general Ward of the Mental Health Unit. And one thing about if you are in a place of unwellness psychologically, psychiatrically, then your environment is extremely important to regain a sense of equilibrium. The lighting the smells, the colours, the textures, all of these need to be considered, and they're not, and so that's... I believe that architectural space...is extremely important in segregated settings, particularly for therapeutic value.

ACT Advocate, October 2020 Zoom workshop with DRC

Problems of providers delivering both supports and accommodation

One advocate referred the problem of providers having “whole of life” control (providing their accommodation and supports) as “service capture”.¹⁸⁷ This came up many times in discussions as highly problematic, with advocates explaining the disadvantages and risk a person with disability may experience when one provider controls their whole life:

“The thing I wanted to highlight is, I think the real issue in these types of settlings is, just to make it very clear, the conflict and the moving away from informed choice and control over the provision of supports. While we're talking historically about the lack of choice, we have to turn our mind to emerging developments in the market that are perpetuating this for people with disability. ...what we're seeing, for instance, harking back to [another advocate's] point about how the NDIS supports these types of settings, is the fact that we're suddenly seeing market development and encouraging these types of supports of housing.

One thing that we have raised to both the Commission and to the agency has been the practice of homes where essentially it's a mini institution, and where a single agency is providing both housing and supports to a person, how that then gives rise to inherent conflict of interest and the potential for a whole host of reportable incidences. The concern is the fact that there has never been that informed choice, and this isn't meant to happen. According to the guidelines, housing shouldn't be provided by a sole provider but what we have noticed is that the guidelines allow for other agents to be able to put in place for excluded costs such as housing, and those costs will be paid to other forms of funding such as personal income,

¹⁸⁷ VIC Advocate, April 2021 Solutions focused workshop with DRC

DSP [Disability Support Pension], et cetera, Commonwealth rent assistance and other forms of income. What that then creates is a new model of housing that perpetuates in all the models that we're discussing, where people don't have the informed choice to be able to live their lives fully, included in society, and that is something that needs to be addressed.

What things are happening in the current system that are giving rise to outdated models? This is not just me speaking lyrical. The report around the Joint Standards Committee released last year highlighted this conflict and it's not necessarily something that is new and it's something that we need to address in terms of housing, as I said what can be done to address unintended and perverse outcomes with current systems and models, that are creating and re-perpetuating of traditional older models of disability care to exist."

NSW Advocate, March 2021 Zoom workshop with DRC

"I just wanted to bring it back to that setting where the service providers are saying that for this to be financially viable, we have to provide you with all of your supports and your support is tied to your accommodation. And I guess there comes that risk of 'if I piss off my service provider, I'm going to lose my house, you know, so I will put up with being potentially abused, neglected, exploited, having restrictive practices put against me because I'm really worried about my housing and where I'll go or if I can find another place in another home –'

[Colleague: "Or I'll lose my community. It's not just that they will not have a home because even if they are moved to another home because they're unhappy with the service provider, they've lost their community and it can be very challenging for people to rebuild that and it can be very challenging for people to get to that if they've moved"]

"...We are seeing even outside segregated settings service providers saying, "No, we must have your full package for us to provide this particular support" which again that comes back to that isolation and the lack of safeguarding for a person where you have the one provider, and often people with guardians, that is the choice that sometimes they'll make, 'it's easier for us to just go with the one provider who deals with everything so we don't have to deal with multiple providers,' you know, and it's done and dusted and then they're, I guess, relying on the provider to do the right thing."

WA Advocates, October 2020 Zoom workshop with DRC

"In addition, if a person is seeking a different arrangement, their housing is a risk because the SIL [Supported Independent Living] provider only supports people with '24' hour supports."

SA Advocate, December 2020 Zoom workshop with DRC

"I know at one point, I think it was last year, there was discussion around changing the guidelines or such that you couldn't have a support coordinator who worked at the same organisation as the SIL [Supported Independent Living] provider. I don't know what came of that, but it was at least acknowledged at a broader level at the NDIA level that this was an issue."

VIC Advocate, April 2021 Solutions focused workshop with DRC

"...that's a big problem in this area as well, [in our] area, that there's providers that provide everything, support coordination, plan management, there's even SIL [Supported Independent Living] homes... it's full control and it doesn't work well and then the client... I know one person in particular, they thought where do I go? They feel they're obliged to stay with that service. I said, "No, you can go somewhere else", but that makes it very tricky for that person to go, "Hang on, I've got a complaint against the support coordinator, or someone in the house," because everything is controlled by the one organisation. It's a real problem. I would think, having a law background, the best way around that would be for the Parliament to pass legislation to say that that's... to rule it out basically, to say that can't happen in the future because that is a real problem. People need choice and control. They shouldn't be controlled by one service, especially if they don't have parents or a person responsible to give them a voice, then they really... they just stay there, and they don't realise that there's other options."

NSW Advocate, April 2021 Solutions focused workshop with DRC

Topic – Criminal justice systems

Advocates have drawn attention to problems with justice processes, including policing, courts and incarceration.

"One of the things that keeps coming up is the poor reporting processes. I've had one person talk about how when they had trouble with police and they put in a complaint to the law enforcement conduct commission, that complaint was then referred back to the same police station where the problem occurred. So, there is a need for some independence in investigation, particularly if there are allegations against policing in some form."

NSW Advocate¹⁸⁸

"There needs to be that circuit breaker, there are so many stories where: 'I got given this label by a police officer, or child protection services, somewhere and that label has continued to follow me. Because I have that label the courts, police treat me this way, and that's where there needs to be the ability to have an independent reporting process, assessment, so that

¹⁸⁸ NSW Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

I don't walk into every court room or police station wearing the same clothes. I'm able to go to somebody who can help me to have different clothes or have someone speak for me in a way that means I'm not tainted by that report my abusive husband put in about me 25 years ago that has followed me ever since.' That independent reporting can be the circuit breaker that allows somebody to start to be free of the system."

NSW Advocate¹⁸⁹

"...we have had a couple of incidents of people who, due to their marginalisation and mental health issues (such as anxiety), have called the police for seriously legitimate reasons but ended getting to the point where the police have charged them with making a false report etc. This is despite having been told in multiple conversations that if you feel unsafe to call the police. A person with an intellectual disability does not necessarily have the insight to determine what is a genuine emergency and what is not. Quite often, once that has been brought to attention, advocates can work things out with police to best strategise and manage. But then it falls into the issue of the plans not being implemented because either they are not circulated or the person you are dealing with moves on."

SA Advocate¹⁹⁰

"I have worked with several clients and in criminal justice matters, sometimes they have witnessed or are a victim of crime, but more often they are caught up in the criminal justice system. Police are ill equipped and sometimes lack willingness to understand the persons disability. I am working with a range of people with disability: intellectual, ABI [acquired brain injury], autism, sometimes psychiatric or psychosocial. Police are often not understanding their basic requirements to have an independent third person when interviewing. It does not matter whether that person is the witness, victim, or perpetrator.

They can become quite aggressive and escalate the behaviour, and often come in with a predetermined outcome as to what they perceive has happened.

I've seen in a couple of instances in accommodation facilities where there is semi-independent living arrangements, perhaps designed to provide housing for people with ABI for example, where there are behaviours and the support worker service may be delivering services around physical support needs, but lack or have very little insight into cognitive impairment, behaviours and communication difficulties.

I have seen one person where there are intervention orders in place by the accommodation service's support worker against a resident, because they cannot manage the behaviours. We are talking about long term intervention orders here. And constantly goading that resident to get them to breach the intervention order where that person has ended up in the criminal

¹⁸⁹ NSW Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

¹⁹⁰ SA Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

justice system, where they should never have ended up in the first place. This person needs support with communication and managing their upset and being able to express their distress about things quite clearly.

Another resident had been left in a standing frame for too long and there was an accident as a result. That resident sustained two broken legs and my client was trying to raise the issue and they breached him for going and speaking to him. I have serious concerns when we have service providers using an intervention order system to manage behaviours. That they are being paid to support that person to self-regulate their emotions etc, and now we have someone who is in the criminal justice system. The police arrived at that with a predetermined view on what had happened. They were not prepared to spend the time communicating with this person and it just escalated from there. Then he was detained and remanded. He had his communication device, walking frame, and mobility aids removed by Corrections. It is just appalling, there is no way to describe this in any other manner.”

VIC Advocate¹⁹¹

“For people with intellectual disability, it starts from the very beginning, often not having the support they need to help them keep out of trouble, and the assumption that if someone gets into trouble it is inherently their fault, as opposed to the lack of appropriate supports being provided through the NDIS or otherwise. The police all too often do not have the skills or willingness to respond to a person’s intellectual disability, assuming they are aware of it in the first place. And that all too often leads to problems escalating: a person is having a blue with a neighbour, the police get called, the police arrive and use formal language that the person does not understand. The person gets agitated and anxious and police respond to that in an authoritarian way. The person gets more anxious and agitated and before you know it the person is in trouble, not just for the general issue, but for resisting arrest and assaulting a police officer as well.

The court system, especially in the local courts, is so rushed and legal aid solicitors have enormous caseloads and often wouldn’t recognise or respond to a person’s disability or provide appropriate communication and support and so on through the system. At all levels there are major issues of disadvantage, and I would argue that is a matter of systemic neglect and in some cases, abuse by police, correctional officers, or whoever.”

NSW Advocate¹⁹²

“...Police would be the most uneducated people I have ever seen when it comes to working with people with disabilities, and with intellectual disabilities....They need to understand a bit more about the people they are working with, and understand the disability as well.

¹⁹¹ VIC Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

¹⁹² NSW Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

...[The justice system] is not culturally responsive or appropriate. The police will say that it is in the justice system - will say that it is, but it is not. There are still problems there. More understanding about what disabilities are, for a start."

NSW Advocate¹⁹³

"I think one of the biggest issues we have seen in our region is that somebody can identify very clearly with an intellectual disability, yet the police will go ahead without giving that person any form of support, with police interviews and carry on without that. A lot of the time [people with disability] don't really understand what they are getting charged with and they agree with what the police say. One of the biggest changes needed is to ensure that people, if they are going to be interviewed by the police, there needs to be a firm support network for that person before being interviewed. That is one of the biggest things we have come across, that there is no support for that person when the police are interviewing them.

...I think a lot of the time it is an excuse that they were not available, if there was some kind of network in place for people. But sometimes I think it is the ignorance or lack of training of police around support services. I think that is one of the biggest things, a lack of knowledge from police around what support services or referral systems, or anything that is actually in place.

Especially the young ones coming in. We had a recent incident where somebody, they did not know there was a referral system, they did not know that these services and support services are out there at all. I think it is very much that there needs to be a lot more education for police, as well, around what support services are available."

QLD Advocate¹⁹⁴

"...we've got teenagers who are going in [to the justice system] with autism and intellectual disabilities - that is not supportive at all, and they're not getting the support or help in the justice system, and it's compounding the situation and they don't know where to go."

WA Advocate, November 2020 Zoom workshop with DRC

"...when we're looking at clients who have had something perhaps done to them and they need to make reports regarding a crime that's been committed or something that they've witnessed, then they're often treated as unreliable and their thoughts and their observations and their witness testimony is often, kind of, seen as lesser than that of somebody without a

¹⁹³ NSW Self Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

¹⁹⁴ QLD Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

disability. That's been a big concern for many clients that we've actually worked with in that particular area."

TAS Advocate, November 2020 Zoom workshop with DRC

"In Tasmania there's supposed to be, within Tasmanian police, policies in relation to how they deal with people with intellectual disability. We know because we helped them in the first instance develop it, but they're supposed to consult. When a person is identified as having a disability, they're supposed to call a third party to assist them, but they don't do it and they will just... people who are accused of serious crimes will just be video interviewed and have no idea about what they're agreeing to or what's happening.

We had one the day before yesterday and he just said, "Oh, well, because they're the police, you have to follow everything that they say." So informed them about their rights, you actually have to follow lawful direction, but you don't have to agree to be video interviewed. They weren't told that by the police.

So people just want to comply and when it comes to court, then they probably agreed to something they had no idea, or they've asked someone about a timeframe and someone with an intellectual disability might have trouble knowing how long it took them to get from one place to the other or what time something in the day happened, and the police had no idea around how to respond to, ask questions to, particularly people with intellectual disability.

But Tasmania had a review into communication assistance a couple of years ago and that's gone nowhere, so there's been absolutely nothing come of that."

TAS Advocate, November 2020 Zoom workshop with DRC

"Yes, I think there's some jurisdictional issues between Victoria police and the NDIS and the Federal Police, where the misuse of funds, NDIS money, results in restrictive practices or abuse and neglect or violence towards a person with disability because police claim they have no jurisdiction because it's federal money. And at times when we've had to get welfare checks because we're concerned about some of our clients in private residences, we now use triple 0 because before when we rang the local police station, they would go around and if no one answered the door, they'd leave their business card under the door for the perpetrator to see when they got home. So it was a terrible situation.

So this jurisdictional issue between Victoria Police and Federal Police, when there's money involved that creates these abusive situations, needs to be much clearer. If it involves an assault where someone has an NDIS plan, that's a different matter. Victoria police can investigate that. But when the money is being used to restrict somebody and prevent them from participating in normal life, Victoria Police have no jurisdiction."

VIC Advocate, February 2021 Zoom workshop with DRC

“Sometimes proactive policing is working well, but sometimes it comes down to the individual police officer and the station. If there is a culture at a police station, there is very little we can do to change it and to get inside to help educate and upskill etc, but other stations are fantastic. And that is huge, that could just be within a couple of catchment areas. Police stations within the one LGA [Local Government Area] could all be different. I have had instances where I have said: ‘don’t go to that police station to lodge your family violence application, go to this other one because you will get more sympathy there’. We should not have to be doing that, we want more consistency. How we get that is a big question.”

VIC Advocate¹⁹⁵

Topic – Child protection systems

“The child protection system sees intellectual disability as a risk factor in the same way that they might with drugs and alcohol. If you have an intellectual disability, it doesn’t mean you are broken. It’s not something that can be fixed. But in fact, parenting children is something that lots of people do, and you need support to do that. Often, we advocate for people who don’t have natural supports or family support in place and have not previously had paid supports to assist them with either.

So the usual story is that children are taken away, they are removed from the care of the parent with an intellectual disability, and inevitably end up in long-term foster care placements until the age of 18. During those years, the parent ends up with access that looks something like one hour per month. There are of course others who have some different arrangements in regards to access, but typically, it’s once a month. Certainly not an opportunity to build a relationship.

The other thing that we are aware of is that the children in those situations come looking for their parents when they are older and their relationship hasn’t been supported or nurtured by child protection services and so it can be quite difficult coming back together as child and parent.”

SA Advocate¹⁹⁶

“There is a distinct lack of programs for parents with intellectual disabilities. In Victoria, there are mother and baby programs for parents with psychosocial disabilities, but those will not accept people with moderate intellectual disability, in our experience, and I feel that it is absolutely imperative for that gap to be filled. A lot of the clients I work with are experiential

¹⁹⁵ VIC Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

¹⁹⁶ SA Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

learners and so need that ability to learn with support and encouragement, as opposed to, "We are watching you. We are watching for every mistake you make and will report that."

That is not a good type of approach. There needs to be something done about the hospital-based programs that are refusing to take people with disability into the program, and I have noticed some gaps that need to be filled in terms of the law. I would like to see this in the actual legislation, which comes under the Children's Court of Victoria, that child protection needs to give opportunities for that parent to learn, even if that's in a safe program. Because I think that would compel some services to open up at a residential level to support that person and some increased supports in the home. The manner in which child protection conducts themselves as well, that needs to be addressed. It is highly adversarial and brutal and unnecessary for anyone to conduct themselves in that manner. I know they have huge workloads in very difficult arenas, but so do all of us and we don't tend to conduct ourselves in that manner. With their obligations, there needs to be something to compel them to meet their obligations because, at the moment, they are a law unto themselves. In terms of parents with a disability who have been in the child protection system themselves, child protection are responsible for where that young person goes to live. In my experience, I've seen numerous cases where young people that have been in the child protection system are placed in supported residential services or boarding houses, and it is just totally inappropriate. And they are in a setting where they are subject to repeated abuse and exploitation, and then, on the other side, I am seeing child protection services where the children were at home with the parent and then they are placed into foster care. The same things that the parent was doing for which the child was removed, child protection gave the foster parent permission to do to the child, such as to stop him running off out of the door, you can tie him to a chair.

They removed the child from the parent for doing the same thing. Something has to be done in a legal stream to address this because it really is... I cannot make sense of it.

You remove a child from a parent because of the way that they have tried to manage supports and then that young boy had significant disability issues. And then you give permission to the foster family to do those same things. I really don't know how to address that in the legislation but that conduct they have accused the parent of doing has been abuse - they are endorsing in another household. I don't know. I am open to ideas."

VIC Advocate¹⁹⁷

"...child safety cuts off pretty quickly when they place a child with another parent or family member, and that is basically okay and they have ticked the box and you can close that file off. But there is no follow-up to ensure that the contact has stayed, or whatever, and the family members have been a law unto themselves. It can be a fight for 2-3 years to get it into court and then the court can say they have not been a significant person in that child's life, even though it hasn't been that parent's fault, and basically the family member has won and that

¹⁹⁷ VIC Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

person has no contact with their child. That is through no fault of their own whatsoever, and the child safety system lets them down, and then also the family law system lets them down, so it's a catch 22 there. Because it takes so long to get it heard in court and you do the parenting mediation and, you know, we know they are not a legal document so they can say 'yeah, yeah, we'll give that person contact' and because it's not a legal document, (while you can get it made into one), but, yes, it is dismissed as well by family members. And then it is back to square one again, and back to court, and by this time a significant amount of time has gone by, and the parent has not seen their child for 2-3 years."

QLD Advocate¹⁹⁸

"...individual child protection workers sometimes, and our experience has been there, have been individual workers who've actually been seeking advocacy input into written and verbal communication with parents with disability about their children who are in care and about access visits. It's rare, it's not supported by the child protection system, and it remains viable only when the individual worker or practitioner is prepared to work with advocacy, but maintaining consistent workers can help that continue.

So there's a lot of shift and change. So if the system was prepared to leave people in their work role, their social work role, whatever it is, with a family in the long term, you're more likely to get better outcomes for those parents with disability. But you also would have the opportunity to challenge that, because what happens where we give good feedback to those workers, and I've been really impressed with a couple of those people. But we're talking about hundreds and hundreds of workers, and for some families they might have 26 workers across a period of years because workers change so much.

So even when there's a good thing happening and you give that feedback, it's fantastic, the system undermines that good practice. And I think that the reason is because these things take time, so to do well by people with disability, particularly I think people with cognitive impairment, probably people with mental illness, you need to provide time to get to understand the person, to work out what it is in your practice that you can do differently... When you get to the end of a program, our experience of the service kind of goes 'oh, you're too broke'. Or 'it's your fault that it didn't work', but it's not the person's fault, it's the fault of the service, or the worker, or the system. So in the child protection system, we see that as being a really significant problem and we would be really keen for the DRC to be taking that stuff up in regards to the consistency of workers for people with intellectual disability, parents with intellectual disability, and the encouragement of workers having more time... you know, it's probably a workload issue, but more time to actually pay attention and to engage better."

SA Advocate¹⁹⁹

¹⁹⁸ QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion.

¹⁹⁹ SA Advocate, April 2021 Solutions focused workshop with DRC.

Children and young people with disability

"...we meet a lot of children... just before they're transitioning out of foster care, a lot of kids that have got disability, and if we're lucky we'll get to meet them when they're 16, but often it's when they're 17 and they are now transitioning to somewhere, often the child safety system aren't sure. ...there's often, if you look at the cases of those kids, then they could have, if they had the right services and supports initially and many years before, then they wouldn't even be in the child safety system in the first place. ...So many kids are ending up at a service of last resort in the hospital, in a hospital setting, which of course is a totally inappropriate setting. But then, when they get there, that's because there is nowhere else for them to go, and then the State Government has nothing else to do other than to put them in a segregated setting from that point. So it's way too late.

There has to be a strategy for prevention because we know what happens with people with disability. From the time they're born, you can see indicators for children that will tell you that this child is going to require more assistance, that this family is going to require more wraparound services and support so that that child doesn't end up in the hospital with the family totally broken down and someone saying they're going to walk them off into the bush and leave them there..

... the state government [...is] responsible for a high number of people. You know, we've got about 10 children on our books at the moment that we're working with long term, just as a safeguarding mechanism, because they're really experiencing that ongoing neglect of a system. And right across the community, because we're not servicing them well, we're not providing them with any real assistance, and that means that they end up not being educated, being in their houses, you know, having increased challenging behaviour due to frustration.

One child yesterday was reported to me that they went into...they didn't want to go in a taxi and there was one taxi provider who was going to take them home, so to get them home eventually after half an hour, someone managed to get them in a taxi. But then when they were in the taxi, they ripped off the handle, they vomited and threw vomit on the taxi driver, all kinds of things happened, and now that child won't be able to get any taxis.

And if you look back, because that child is 12 years old now, this child had indicators that we needed to really do something about when that child was 3 years old. You can see the writing on the wall now. You can see well, they're going to be at home more and more, they're already in danger when they're at home - not from being abused by their family member, because child safety look at them and say oh, no, they've done an assessment and they've said well, they're with their family, they're fine - but at some point, because that child is getting more and more frustrated and they are going out less and less, then that's just going to blow. You know what's going to happen and it will again, be that... that child becomes segregated, and they'll have to go into care, and it's all totally preventable."

TAS Advocate, November 2020 Zoom workshop with DRC

“...from some experience of people that have grown up in child protection, it seems that those people get funnelled into group home settings as they reach the age of 18. And there is seemingly little involvement from the Department to have a broader interest in the person’s wellbeing and the potential of the individual and them living independently and those types of things. It seems to limit people's potential, in some regards. The view is that they get moved into a group home and that’s just where they will stay.”

SA Advocate²⁰⁰

“In Queensland, there is often a standoff between the NDIA and Child Safety regarding disability related supports for children with a disability who are placed in Child Protection.

Where a parent attempts to relinquish custody of a child with challenging behaviours due to being unable to manage the child in the family environment under current support arrangements, Child Safety has refused to accept the relinquishment. Children receive very limited NDIS supports, and the NDIA Planners also refuse to participate in Stakeholder meetings with Child Safety. This makes establishing the right set of supports to mitigate the risk of relinquishment and maintain the participant’s family relationships is difficult to achieve.

I also understand that, in cases where a child with challenging behaviours is a state ward, Child Safety (as Guardian) has used chemical restraint of children to control their behaviour. Child Safety has also resisted controls being placed on chemical restraint of state wards and refused to comply with requirements for behaviour support plans.”

“Children in State Care who receive NDIS funding need to be better protected by the NDIS Quality and Safeguards Commission in terms of use of restrictive practices by QLD Child Safety as guardians of state wards.

The QLD regime controlling restrictive practices (and in particular chemical restraint) should also apply to children (currently only applied to adults)”

QLD Advocate²⁰¹

“With the experience of children during the child protection system, any child where we had been invited by someone to be involved with regards to advocating for the child, the child protection system just says no. They see themselves as the advocate for the child, even though we would all, I think, know that the decisions being made are not always about the best interests of the child but resourcing and all sorts of things, and there are competing interests in terms of how child protection systems serve the children they are supposed to be serving. Even when we have been able to be part of the conversation around what is

²⁰⁰ SA Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

²⁰¹ DANA's 2020 Child Protection Systems survey, Response from QLD Advocate

happening for the child, decisions are still being made with regard to children and placements, again, based on resourcing and those sorts of things, is what we see predominantly.

For children to be able to access any kind of direct advocacy or assistance themselves, in South Australia we have the Commissioner for Adults and Young People, but it is only the child who can go to them. Nobody can go to them representing the child.

The child has got to know about them first, and have access to and be supported. And if they're going to the Commissioner because something has happened to them within the system, who will support them to access that?

If a child raises, there are children who might raise some issues with the particular social worker assigned to them and they won't act on that and, if they do, it will ... not result in anything more for the child. If the child says they want to see their parent more, they'll say 'well, it's not in the child's interest'. If they want the child to see their parent less, they will say 'it's the child's choice'. They will use those arguments to underpin their view of what something should be, rather than for what the child is wanting or what is in their best interests."

SA Advocate²⁰²

"...I've been working with a young adult, he was removed at the age of four from the father's care and was placed in the permanent care of grandparents. No one had followed up from Child Protection as to the suitability of the grandparents as an alternative. I think it was just ticking boxes and getting a family for this young four-year-old to go to. The abuse continued to the point that police have phoned and said the grandfather drove by and threw him out of the car. There was no follow-up. The concern is, from there, these people end up in the criminal justice system... so we have a young man who was left without support and there was no follow-up from child protection, and the suitability of the grandparents was not looked at, and he is now in the criminal justice system and has some very complex trauma presentations. In fact, most of his criminal justice offending behaviour is related to trauma. There is the family violence situation and it is significant. There is usually an undercurrent of that somewhere. Whether it is because the parent has been removed themselves from a family violence situation, or they have been placed with someone and put in a placement where family violence is happening. It is significant and it is a problem..."

VIC Advocate²⁰³

"And then you have a child with a disability who has been through 10 foster families because of their behaviours and end up living in a hotel, for the department to then give up because they have run out of foster carers, and give them back to the mother, and the mother does

²⁰² SA Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

²⁰³ VIC Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

not have the skills to do it, you know, so they are set up to fail. You've got one way when they are taking them away, but sometimes it's giving those children back too soon without the support in place. Children being removed at birth... that their child is being removed because they have a disability. Nobody can tell me that when it is found out that she has a disability, and she is pregnant, that that is reported to the department. They should be proactive - working with them straight away to see what their abilities are, before waiting until it's too late and then just taking the child. Because it's devastating when the police are there holding back a father who, because of his disability, doesn't understand why his baby is not going home with him. That is not okay, when they can be proactive and work with them prior."

QLD Advocate²⁰⁴

"Individual advocacy is important, but where there is a systemic/cultural problem in an agency, then this needs to be addressed at a higher level rather than just chipping away at each case one by one. Advocacy can also help parents understand their rights, both in cases where they want to prevent their child being taken away, but equally so if they feel like they can no longer care for their child under current arrangements."

QLD Advocate²⁰⁵

Parents with disability

[Child protection matters] "are typically protracted and unsatisfactory in many respects. There is very little understanding or at times willingness to understand the needs of the person in regard to how a person might process or respond to information and processes. Parents with intellectual disability routinely have their children removed from their care based on intellectual disability as a risk factor. There are no services that can or will work with parents in a sustained or potent way and certainly not if their children are in alternative care."

SA Advocate²⁰⁶

"All of the women I support whom have lost access to their children via the Child Protection system are women with disability, mostly intellectual, cognitive, psychosocial disabilities. These women all report a lack of engagement from Child Protection in discussing appropriate supports for the women going through the processes, understanding their rights, ensuring they have adequate support with the process and understanding the legal system. In my experience these women with disability are only appropriately engaged, or even responded to, when an advocate is involved sadly. Most of the women experienced inadequate supports

²⁰⁴ QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

²⁰⁵ DANA's 2020 Child Protection Systems survey, Response from QLD Advocate

²⁰⁶ DANA's 2014 Rights Protection, Justice and Legislation survey - Response from SA Advocate

prior to engagement with Child Protection and so, therefore, this is a major failing of our systems to ensure there are preventative supports to ensure the protection of families.”

“Ensuring people are aware of their rights, that CP [Child Protection] workers are aware that people with disability, especially women with disability, are at a higher rate of risk in regards to experiencing violence, and support women to leave violent situations, with appropriate supports to ensure the parent with disability is supported with education, practical support and adequate long term supports to protect themselves and their children, instead of removal being the easiest option.”

VIC Advocate²⁰⁷

“...We came up against quite a lot of barriers in the beginning, where they just said that if it was a child protection matter then family services take care of that. There are no family services other than child protection, because if you try to engage with the service around any support around parenting, as soon as they know that child protection is involved, they just take their hands off and say, "No, we can't help." They just assume that they will be providing the parents with the support that they need, and we know that they absolutely do not.”

SA Advocate²⁰⁸

“...it might take six to 12 months to engage with the Department for some clients. It's this entity that is massive. It's like having to deal with the police every day. It's that authority figure and it will take them a lot longer. Is two years appropriate? Not only that, so many people are slipping through the gaps, where you have the recognised entity, but do you have something similar to that with someone with a disability? They go to these meetings and sign these documents and don't even know what they are, and are just hoping that they are being told the truth. We have even had families who have signed their rights over to another family member. They would have been better to have given their child to the Department rather than to have signed over their child to someone. Then to go to family court and find out that all the allegations were unsubstantiated and have to go through Family Court to get their children back, and they couldn't get them back. And they did nothing wrong.”

QLD Advocate²⁰⁹

“...the amount of CSOs [Child Safety Officers] that sometimes a person can go through, and then they are told about not working well with child protection, but when they've gone through 16 in a year, how can they build a relationship with those people? Every single time, the

²⁰⁷ DANA's 2020 *Child Protection Systems* survey, Response from VIC Advocate

²⁰⁸ SA Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

²⁰⁹ QLD Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

biggest story we hear from our clients is that we always feel that we, every time we get a new CSO, we have to start all the way at the beginning again and go through all the hoops that we've already done...We've already done this, but now we have a new CSO and so we have to do it all over again." We hear that often. The amount of CSOs that they get, and they have to go through the same things again, they feel that they've met the department's goals and then they find out that there is something wrong."

QLD Advocate²¹⁰

See also comments on [Child Protection Systems](#) and [Parenting supports and NDIA](#) in Appendix A below.

Topic – Workplaces, welfare systems and employment services

"In the bigger picture around barriers to employment a lot of people want to talk to me about Centrelink and job services providers, and essentially that is part of that picture, although a lot of the time it relates to the specific welfare that they're trying to access or things around that. I have had a lot of negative feedback around the system, the job service providers, and the pathway now, especially for people on Newstart."

WA Advocate²¹¹

"We think that, yeah, there just isn't enough to live on. I mean, if a person has, say, an aged care pension and they're supporting other family members who, for whatever reason, have a Centrelink debt or just haven't had the ability to report to Centrelink, then they're all brought down to live in poverty."

An example, yesterday one of our clients, both the mother and daughter have complex disabilities. One of our advocates tried to support them to go to Centrelink. Now, because of COVID rules, you have to stand outside of the Centrelink here. It's 41 degrees. There's a line up. Both people have disabilities. There's no way to make an appointment to come in. It ends up that those people stood there for a period of time and then just gave up, you know? They just make it so hard that they can't, you know, they want to try to do it, but they just can't."

NT Advocate, November 2020 Zoom workshop with DRC

"I think employment is quite a big issue. Firstly, employment needs to be inclusive, and workplace complaints have not worked out well for the majority of people I have ever supported. Covert bullying is a typical example. People have a right to pay their bills, yet

²¹⁰ QLD Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

²¹¹ WA Advocate, "Advocates Zoom In On... *Barriers to Employment*" October 2020 Zoom discussion

social factors are more important and override this more often than not, this is seen everywhere.”

*VIC Advocate*²¹²

“...everybody out there is poor. You don't have enough money. So what we're doing is creating a situation where people are scrambling over one another to try to put food in mouths. We actually create the abuse and neglect that happens in those communities by keeping people in poverty.

I think if we addressed the poverty that people are experiencing, some of the abuse and neglect we see would disappear, and some of it did disappear when people were getting additional money through COVID. I think that has to be a long term strategy to get everybody up to a level where they don't have to be taking money off someone with a disability in the family who's getting a regular pension or the old person in the family who's getting their aged pension, where everybody is looked after, where people are not forced into a situation where to survive they have to exploit one another.”

NT Advocate, November 2020 Zoom workshop with DRC

“The Disability Employment Services are not flexible enough and are under resourced. Unemployed PWD [people with disability] lack support to find and apply for jobs, and to find a job that 'fits' well with the person.

PWD who are already employed have no access to employment supports to advance their career or find a more fulfilling/better paid job. They can only access support to remain in the same job, even if they dislike the job, it pays poorly with poor conditions, and they wish to move on to a new job. There is discrimination among employers creating barriers for PWD to enter the workforce.”

*ACT Advocate*²¹³

“...people with acquired injuries struggle to find appropriate employment (usually due to employers' attitudes) following rehab and are forced to turn to ADEs [Australian disability enterprises], but as many have said, to them these settings reinforce a sense that they are defined by their disability.

As one person said to me, "I live with disability, I don't want to work 'disability'" too. As has been said, there needs to be attitudinal change by employers and workplaces, which can in part be facilitated by providing resources and subsidies to former employers to make

²¹² DANA's 2020 *Safeguarding rights and wellbeing* survey, Response from VIC Advocate

²¹³ DANA's 2014 *Economic Security* survey, Response from ACT Advocate

reasonable adjustments following a person's rehab journey when they return to the workplace (i.e. greater resources for Job Access etc.).”

NSW Advocate, March 2021 Zoom workshop with DRC

Australian Disability Enterprises

“...people have self-referred, generally around having an independent advocate present when they're having their annual employment assessment, yes. And we've also worked with people because of the wages structure and people who believe that their work, and it definitely would, be comparable to an able-bodied person which is how they do their assessments, and we've been to the Fair Work Commission with clients in the past. It's a real struggle. The whole way it's set up is confusing and really, really hard for people to fight in terms of wage discrimination.”

SA Advocate, December 2020 Zoom workshop with DRC

“...we sometimes get self-referrals and I guess that the majority of people we advocate for aren't in any kind of employment. But I have had many referrals from ADEs [Australian disability enterprises]- who'd like an advocate along while they sack a person, so they don't look for advocates prior to that, but they've now decided that whatever is going on in that ADE... and so that's kind of -mind-blowing for me, that these are congregated settings where people with disability, this has been created for people with disability, yet they can be sacked from those places. So, yeah, I think that's a huge problem in regards to them not believing or seeing that advocacy might be a helpful way before the person gets to a situation where they're trying to push them out the door.”

SA Advocate, December 2020 Zoom workshop with DRC

“There absolutely is still not an approach of ‘this is a pathway to open employment’. Once they get their hands on people and they're productive workers, they keep them at all costs. And there's still not enough focus on moving people and using that as a transition, even though we think they shouldn't exist at all. So, yeah, that lack of opportunity to transition people into open employment, or even talk to them about what it is they actually want in terms of their employment goals. It's very limited.”

TAS Advocate, November 2020 Zoom workshop with DRC

“There is still definitely people, often just after college or high school for the rest of Australia, and they work for [ADE] and 20 years later they're still doing the same thing, they haven't moved, with no opening to open employment. I don't think that's changed. We can't see ...that there's any effort for the ADE themselves to let people... try to get people open employment. They've got good workers who may be very, very successful in open

employment, that's for sure, and they hang on to them because they are the ones who make them the most money with very little pay."

TAS Advocate, November 2020 Zoom workshop with DRC

"...the comments that I'll make probably come more from conversations through self advocacy groups and peer support groups. But I think certainly, yes, people are really vulnerable in the settings, again for all those reasons that it's closed off. There isn't the natural interactions with the community, there isn't the traffic that's going, you know, through.

...people go to an ADE and they get stuck there, and often that's actually done in the name of 'it's their choice'. But the opportunities to actually revisit those kinds of, those sorts of impacts on their life, just aren't there and the support to actually do that.

One of the things that people have raised often, though, really is about what happens in an ADE when there isn't enough work and when people are actually bored out of their brains and some of the kinds of, the impact that that actually has on people's behaviour, on their communications, and the whole sort of interactions then that happen between people. And again, that kind of triggers off that whole thing again of, "Oh, the person really can't be here, they actually really need to be relocated somewhere else" rather than actually addressing some of those core issues."

TAS Advocate, November 2020 Zoom workshop with DRC

"I think what would be helpful, particularly through engaging with the policy and research team, is if the DRC is looking at what a transition away from those segregated settings look like - That's work I don't think many people in our sector have done, and it's one that I want to do here at [NSW Advocacy organisation]. But it's very hard to see how we can - for the ending of employment of segregated settings, we don't know what it looks like elsewhere. So it will be really interesting to see where it's worked well, and what that transition looks like, because that transition plan will be part of obviously ending those segregated settings, but also it will address the concerns that people have around that pathway that I was alluding to earlier in this conversation where you have got a segregated setting from one to another. So we have to make sure that there is that conversation around that pathway from schooling to work, that that is factored into what that transition plan looks like. If we don't do that work, then ending those segregated settings won't happen."

NSW Advocate, March 2021 Zoom workshop with DRC

Topic – Education

"People with disability are experiencing abuse and neglect in education settings via the lack of support from primary schools/secondary schools for many students with disability. The

lack of support surrounds funding issues for students i.e. fitting into the funding box, support aides providing limited support and their lack of disability appropriate training, behaviours of concern, issues for schools understanding their role to engage supports before limiting student attendance, student supports for students with behaviours and students vicariously experiencing behaviours, and appropriate specialist advice in supporting some of the students with disability with issues with behaviour. Education providers need to ensure they are inclusive and supportive of students with disability.”

VIC Advocate²¹⁴

“We do a lot of work with the education system. What we find, I'm sure other advocates find, again it seems to be primarily around the ASD [Autism Spectrum Disorder] diagnosis and also trauma. Children often with behaviours that are considered challenging can find themselves excluded from schools quite often, or under wrap funding where they have a one-on-one teacher and not actually, maybe even off site, so there's that sort of segregation that you might want to consider as well, or not being able to access what the other kids are accessing.

...On the side of that the perpetual placement in different schools and trauma children experience from that, again it's the department not taking responsibility for... and what I'm finding in the secondary schools now is a coercion to get children into the FLO [Flexible Learning Options] program and often they're trying to be placed outside of the school into a community program where they don't have the proper training to manage these people... they look at the behaviour as naughty children or naughty teenagers and they're not actually looking at their education needs, they're not being addressed. They're not providing an individualised program, they're not looking at again what their needs are, the underlying needs and what they're seeing is the behaviour. But they're not addressing it could be a sensory need, it could be all sorts of things that are coming into play. So there's lots of different segregation that's happening within the education system...”

SA Advocate, December 2020 Zoom workshop with DRC

“Education settings - segregation, alienation, lack of access, lack of status, lack of witnesses ie. reduced accountability (particularly for students that are non-verbal), lack of transparency, lack of independent complaints body, student not being seen or heard by broader school community, creates a culture where the student with disability is perceived as "devalued" generally and not belonging - seen as "them" rather than one of "us" - This justifies the view that they don't belong in a regular class or extra curricular activities such as camp or swimming carnival. Usually there is a power broker, an imbalance of power for example, between principal and parent, principal and teacher, parent and teacher, teacher and student

²¹⁴ DANA's 2020 Access to Education survey, Response from QLD Advocate

(especially in a segregated setting). A lot of buck-passing and delays by reporting bodies, as well as poor coordination and collaboration at every level, for example, between and within State and Federal Departments and within the Department of Education itself.

Our phone enquiries in relation to education, gatekeeping, inappropriate suspension, restrictive practices, and forced partial enrolments have doubled over the last 5 years. Cultural history of devaluing people with disability, such as the eugenics movement, and parents being told their kids with disability were uneducable up to the 1950s. The education system condones a culture of suspension and exclusion, teachers feeling ill prepared and lacking in confidence. The culture of exclusion still exists, the mindset that kids with disability "are segregated for their own good." Governments hand over all aspects of care, accommodation, personal support, transportation, planning, communication to a single organisation."

NSW Advocate²¹⁵

"...having restricted hours, they're allowed to attend school and some of them being segregated from class and placed out in the corridor or in the gym or in the library, but not being allowed to participate in the classroom activities. And often we're finding with the DRC submissions we're doing, it's when there's been an end behaviour that's been the outcome of a whole lot of bullying or things leading up to it. And the school doesn't look at what led to the final incident, they just respond to the incident and the child with disability that's exhibited some behaviour, that's what's come to the notice of the principal or the teacher and they just don't, they might have antibullying policies or whatever, but they don't look beyond the final behaviour. They don't look to what's happening and trying to address that to prevent these things happening in the first place."

SA Advocate, December 2020 Zoom workshop with DRC

"There's a new program that the Department of Education have got for State Government, ...And my understanding is that it's about acknowledging that teachers and people working with children with challenging behaviour require additional assistance and understanding beyond the behaviour assessments that have been done, and any recommendations that fall under those assessments, and that it's more to do with if a child needs some kind of restrictive practice or movement or something. I mean, a lot of the practices may happen because they're keeping children safe, for example, so they might be even physically steering someone away and then there's a whole range of , I don't know, because it's new, how many schools are taking up that option to get that to improve their understanding of how to work with those children.

²¹⁵ DANA's 2020 Segregated settings survey, Response from NSW Advocate

So it's something that we can talk to the Education Department about more. But I do know in Tasmania in the private school settings that where children exhibit challenging behaviour they are just excluded. But that's the usual response and [they are] usually told that they're better off going to the state system who have been practising inclusion, or they've had a policy for a long time around inclusion and probably they've got more supports in place for children who have challenging behaviour."

TAS Advocate, November 2020 Zoom workshop with DRC

"...segregation in the education sector is something that I come across a fair bit. And that's not regulated at all. I just think greater transparency in the schools would be a good thing. [in mainstream schools]... my experience has only been with people on the autism spectrum and it's not a complete segregation 100% of the time, but they're often taken away and placed segregated and by themselves and that just causes more behaviours for them, and it just exacerbates the situation. And by the end of the term, they're quite often frazzled."

QLD Advocate, December 2020 Zoom workshop with DRC

"... I think the segregation is starting at schools, and that's what we're teaching kids that it is okay to put children in disability in one place and children without disability in the mainstream schools. And that is going further with every single part of our life and that is a culture that we created..."

QLD Advocate, December 2020 Zoom workshop with DRC

"...there are three issues in terms of reducing restrictive practices, and the first one we have already commented on is timeliness. If something is not handled quickly, then how does it improve? So if there's no assessment done quickly, if a school has got a restrictive behaviour support team and they don't actually provide data, which doesn't get processed quickly and things don't change, it means that something can continue for a long period of time. There is also the issue of independence. You need to go outside of the body in order for accountability to be happening, whether that's outside of the Department of Education, whether that's outside of the organisation that's actually managing the group home, you need that independence. You need that independent oversight and you need that independent accountability, and I think there is no accountability, there's no target set. There's restrictive practices in place. How will that change? And you see that particularly with suspensions, which I would say is a form of restrictive practice. So often suspensions are not followed up with improved changes. It's like, OK, your suspension is over; come back to the same status. And suspensions are designed to be a support ideally. The school takes a break so we can put in additional supports. So often they don't happen, so you don't get a reduction in

restrictive practice because nobody's collecting data, nobody's responding to it quickly and they don't have an independent accountability to encourage that to happen."

NSW Advocate, March 2021 Zoom workshop with DRC

"My experience has been extensively in the education department, and I believe there is a significant issue in a lot of schools where they are not amending the curriculum and the environment for people with disabilities, with children with disabilities, and, therefore, they use that as an excuse when the children can't cope, to seclude them. I have had stints where children have been locked in rooms without adult supervision or put in a corner and left there to stand for hours on end, and I think that is a significant problem in the education department, that these measures are being used as a bandaid approach rather than looking at the curriculum and how we can adjust the curriculum for that child. I believe it's quite a significant issue across New South Wales"

NSW Advocate, March 2021 Zoom workshop with DRC

"I think that NDIS has encouraged some of those [segregated] schools to continue to build, but the issue is so often the fact that you are secluding people. You're actually developing cultures that not only condone, but encourage, seclusion and being separated from the rest of people's peers, people's community. And so often what it means is that people can be at greater risk in a secluded setting because there are less voices, there are less eyes, to see when abuse, neglect and exploitation actually occurs. ... I am not seeing examples where moving into a segregated setting means that people have improved outcomes."

NSW Advocate, March 2021 Zoom workshop with DRC

"Restrictive practices that are often not thought of are of people being physically "locked out" of education, including limited enrolment and suspensions"

"...I know of one regional school where there is a special class which is behind the fence, which the other students call "the cage", and that's what's happening in one of the regional schools. So just because they're not on a different location doesn't mean that that segregation, and that alienation, and that labelling doesn't happen."

NSW Advocate, March 2021 Zoom workshop with DRC

"I have seen that specifically, actually, to do with my daughter and I will speak personally to that, in the education system, where for years we had a head mistress or a principal whose philosophy about education with disability was poor and continued to be poor. So we were working in an uphill battle where the teachers wanted to make the adjustments but the

principal didn't. Sometimes I feel that this is the same process. We, as individual advocates, are trying to push up change from below up to the above and, yes, that can work in many circumstances, but the difference was when a new principal came on board who had the philosophy that all children with disabilities have equity of access to the curriculum, that they weren't doing me or my daughter a favour in changing the curriculum, and that not only changed things for her but it changed all our vision, equity of access, for the department of education."

NSW Advocate, March 2021 Zoom workshop with DRC

"...we would like the DRC to focus on disability training and awareness in the educational context and the regulation of Restrictive Practices within schools, with a focus on reduction/elimination; strengthening compliance with Disability Standards; and auditing schools, all schools to be bound by the Human Rights Act in Queensland (not only public schools)."

NSW Advocate, April 2021 Solutions focused workshop with DRC

Topic – Health

"I'm wondering if there's any thought around hospitals. A couple of areas around that. With restrictive practices, a person's capacity to make choice, and also family input, I think that might be something that you might want to consider and get some input around. And then the other side of it would also be around, this may have been looked into, but just around the NDIS, people not having appropriate funding and then being kept in hospital because there's no place for them to go, and then advocating for them to get NDIS funding because of their needs. And that might have resulted from lots of things.

I mean, they might not have had disability to start off with. It might have been a result of an accident, or just that family members are no longer able to care for them. But I think that the hospitals could be considered, that segregated sort of environment, and that might need to be considered because there are people in hospital situations who've been in there a long time. We know of a couple of cases and they're waiting to get appropriate funding."

SA Advocate, December 2020 Zoom workshop with DRC

"Very recently the South Australian Government funded placements for people who had been in hospital, people with disability who did not have a medical need to be there. It was a housing need. And they were moved into what was a rehabilitation hospital, so it was just moved into a ward setting with a mix of people, mostly older people but a couple of very young people as well, and again just confined to single rooms. I've been there to visit on a number of occasions and it's bloody appalling. That was the South Australian Government's

response to there not being... any response to those people in regards to housing and NDIS supports.”

SA Advocate, December 2020 Zoom workshop with DRC

“I think in order to understand what kinds of changes are needed, we also need to think about why restrictive practices are used and one of my concerns is that there may not be enough attention given to those underlying reasons and some of the connecting factors. Now, I may be wrong here, but it seems to me pretty obvious that there's a reality that any care setting will have limitations of resources and staff, and the more acute those are, the greater will be the pressure to look at other ways of managing risk like restrictive practices. And perhaps the other thing there is training of care professionals. I'm thinking of health care particularly”

WA Advocate, October 2020 Zoom workshop with DRC

“I wanted to also raise the fact that recently a member at QCAT actually spoke about advocacy in a very poor way. She actually said that she didn't have a clue what an advocate did and actually belittled my role so that the other people who were making the application refused to even speak with me or work with me at all. And also it's not just the Public Guardian and QCAT [Queensland Civil and Administrative Tribunal] members, it can also be the hospitals, and I have strong evidence where the hospital just absolutely would not work with the advocacy worker under any condition.

I think, it's not only a breach of the national Charter of Health Rights, but Queensland's Charter of Health Rights, so Queensland's Human Rights Act, that despite these tools that we still have major bodies, CEOs of hospitals and individual doctors, who decide that they don't want to work with an advocate, especially when they're trying to discharge someone out of hospital on restrictive practices and behaviour problems into nursing homes, into locked dementia wards of nursing homes, you know. And an advocate is only trying to do their job. So we have lots of problems in Queensland.”

QLD Advocate, December 2020 Zoom workshop with DRC

“I'd like work to be done, and that is... informed consent and particularly for these people that have challenges in getting their information out, and particularly those who are under a chemical restraint as well.

So some of the work that I'm doing in my [family member's] support is I realised that he was taking some medications and nobody had ever explained to him why and what they are for and what are the potential side effects. So we're sort of trying to improve his ability to communicate symptomology and what might be going on for him without actually giving that context behind it. And I'll guarantee that there will be no participants, or very few, who've ever

been given information around their medications in a way that they can... there's this assumption that they won't understand, but there's no effort in delivering the information in a way.... We've had to go to significant lengths to deliver him that information, but we are seeing that it is actually making a difference. So how many of these individuals have participated in their plan reviews in any way at all? How many of them even know that there's a review happening right now? This is really basic stuff around informed consent and it's not happening."

VIC Advocate, February 2021 Zoom workshop with DRC

"I've certainly had a case, it's quite a while ago, where a doctor, you know, just prescribed it, you know, because the health staff asked for it and there's also a problem, you know, down to... a person with intellectual disability not being allowed by the GP surgery to even call and make their own appointments. That's a recent one, you know. So the culture in those GP surgeries, for example, you know, is so that 'no, no, no, this person can't do that, the carers can only make the appointment, the person can't make the appointment and the person cannot inquire about an appointment.' So I tried to add my client into a call with the surgery so that he could inquire about the appointment. No, wouldn't let me do that. So there's a cultural issue there and a view of people with intellectual disability... that they have no capacity."

VIC Advocate, February 2021 Zoom workshop with DRC

"We had a similar case, a client with an intellectual disability and being prescribed Valium, but that being used for other reasons in the group home they were living in, and it took a lot of persistence with the advocate and the NDIS support coordinator to have that revisited. So it's overt use and the misuse of medication too."

VIC Advocate, February 2021 Zoom workshop with DRC

"Have seen a person's medication tripled over the course of a year. Reports went to Senior Practitioner as required. Not even a question asked. Meanwhile client was groggy, unwell, and other side effects. All prescribing was based on account of support worker - in one instance the SW [support worker] was on their first shift ever, and took client who they had just met, to GP. GP prescribed additional medication based on SW report."

VIC Advocate, February 2021 Zoom workshop with DRC

"Definitely an issue with many doctors holding a view that people with intellectual disability lack capacity - writing evidence that hold in VCAT [Victorian Civil and Administrative Tribunal],

Guardianship orders without proper investigation and understanding into the person's capacity - leading to them to... potentially unnecessarily, being appointed Guardianship"

VIC Advocate, February 2021 Zoom workshop with DRC

"...about eight years ago I was rung up at 12 o'clock midnight to get to the hospital as quickly as I could to save a man's life because the doctor was going to take action that would cause him to be dead in the morning. I was called by his father, who was racing from Toowoomba to get to the hospital. The mother, who was dying of cancer, wanted her son to die at the same time or around... her and this man had a bladder infection and the doctor had decided that he would withhold antibiotics because if he did so he would, the man would be dead in the morning.

So I raced to the hospital and had to stand up against a very abusive doctor who said what he was going to do, and that I had no standing, and I said I was representing the views of the person, the disabled person and his father and that I was authorised to do that and I threatened the doctor that if he did so, if he was making such a decision, it would have to be approved by QCAT, and if he did so, it would be all over the media in the morning and that I knew how to do it. And I did threaten him, but I did end up saving that man's life, and he's alive today. The mother is deceased, but the father is looking after him today and he's still very much enjoying life."

QLD Advocate, April 2021 Solutions focused workshop with DRC

"...a hospital kept a person in hospital against their wishes because they believed the person was at risk, and because they assumed there was a guardian. This resulted in the person being invoiced for a non-medically needed hospital stay. Advocacy was able to ensure that the person was able to act on their own wishes, challenge the charges and ensure that services and supports were available for the person to return home."

SA Advocate, April 2021 Solutions focused workshop with DRC

One advocate identified health professionals as potentially playing a safeguarding role in relation to group homes and other segregated accommodation settings, and as a source of referrals to advocacy organisations:

"...it's really important to, you know, health professionals, GPs, podiatrists, people like that, because you think about who's going to go into these homes, who's going to see them? Because obviously the workers in there aren't going to be really reporting it to us or referring to us, but by getting the word out about advocacy and our services to, I guess, allied health professionals is really important. I find that makes a big difference in our referrals around these sort of matters. That's where we find they come from, and so that's where we target when we go into community and we're talking to organisations. That's how we target who we

target, so, therefore, we're making sure we're going to reach the clients, because when that podiatrist goes to see that client, they will be sitting there and see something and then potentially refer to us."

See an example of healthcare rights at risk in the case study under Appendix A: [Meeting the needs of women and girls with disability](#)

Examples - Fear of retribution or reprisal

"...there's been a real lack of certainly within Tasmania, a real lack of creativity in terms of other accommodation models. It's like the five-bedroom group home, that's it. There's lots of great creative different ways and the evidence says that people living with profound disability can live successfully in the community with the right support, but there's a lack of will within the NDIS to actually enable that to happen. So as a result, you just end up with your standard five-bedroom group homes, which is where lots of abuse happens.

The other thing that we've seen here, and particularly in the northwest coast, is people being evicted because if family start to ... ask questions, if they don't like questions, and where tenancy is tied to the provider, then people don't have a choice to change services if they're not happy and what happens is they're just asked to leave and pretty much they're evicted.

We've had, what, three of those in the last really little short time where people have just been asked, because the families have said "this is not good enough" and have started to ask questions and demand for better.

...what's happened in every single one of those cases is that the family have been intimidated and they don't want to pursue it any further. There are two that are going to end up with, so they've basically... basically they've said they don't want them, it's not going to be a very nice place for them to live anyway, and so we're just going to find somewhere else because the families don't want to, they don't want their family member living in an environment where they think they're not welcome and that they might get a hard time. But at least two of those issues are in the process of making a submission to the Commission...

It seems to be, it just seems to be that that's the go-to now for at least a couple of providers – 'Oh, well, if they're not toeing the line, we'll just ask them to leave.' At least in one of those cases the Safeguarding Commission were completely useless. It was terrible. It was like you may as well save your energy."

TAS Advocate, October 2020 Zoom workshop

Examples - Neglect

"a young woman with cerebral palsy, completely reliant on her NDIS supports to get her in and out of bed, in a wheelchair, feed, all that sort of stuff, the problem happened when her

electric wheelchair broke. It wouldn't work, and the agency's response to that, the service provider's response to that was 'It's a Statewide equipment program which does these repairs on these things in Victoria.'

They came and got the wheelchair, but our client was in bed for a week and wasn't able to get out of bed and was left for six hours a day, incontinent, with no supports over summer. Nobody in that organisation had thought about hiring one temporarily, or approaching the NDIS to use some of her funds to hire another wheelchair so she could at least get out of bed. She spent seven days over summer in bed until (someone) found out about it and that was so discriminatory to leave her in bed like that when it would be easy to hire one to replace it, but they didn't do it. So she was restricted to bed for a week over summer, no air conditioning, appalling abuse."

VIC Advocate, February 2021 Zoom workshop with DRC

"I find that people are isolated, even within those group homes, into their rooms. I find people have been left in their chairs. Their chairs have been turned off. I'm talking about a motorized wheelchair and if they are nonverbal then they're stuck in that chair facing a wall for the day without any ability to mobilize themselves, I've witnessed that... [This person has] a, quite a profound speech impediment, but I mean it's not hard to interpret what they're saying. It really is ... a choice of support workers to ignore them because they don't like that person. And so yes, that person has been parked and ignored and so behaviours then arise from that, that may be not appropriate, aggression, and then we then go into the territory of restrictive practices, using psychotropic medications and / or intimidation - you know, bullying, standing over the power imbalance, is very much there."

ACT Advocate, October 2020 Zoom workshop

"The scary thing is you have a person who has signed a document and have limited reading and writing skills and might only be able to do their name and have basic reading skills, but they will not understand the jargon and everything else, through the documents, the paperwork, and the way that it is explained is horrific, really. They need somebody to support them through those processes when they are signing paperwork, without a doubt. As far as I am concerned, that area has massive neglect. Knowing that person has an intellectual disability and making them sign documents that they do not understand is massive neglect."

QLD Advocate²¹⁶

"I mean, what we find is people from remote communities want to continue living in remote communities. People with disability out there... I've had one person say to me that they would rather live in Alice Springs and that person was a lady with a cognitive disability who was

²¹⁶ QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

being sexually assaulted by someone in her community on a regular basis. And she put up with that for probably, possibly the first four years that I worked here where she continually did not want any intervention or support if it meant that she would have to leave the community. She would rather put up with the fact that she was going to be sexually abused on a regular basis so that she could continue to live on country and continue having her family around her. ...everything is relative and people will know the difference because, especially our clients, are coming in to town regularly and having respite and being looked after properly when they're in town and then they will go back out to a very, very neglectful situation where sometimes they're not getting enough food regularly, where sometimes someone in their family is, because everybody is poor, everybody doesn't have enough resources. ...when every single person in the house doesn't have enough money for food, people with disabilities are often giving away their pension so that other members of the family can have food or there'll be someone who is exploitive in that situation who needs access to alcohol or who is using drugs and will take the money away from the person with the disability. Demand-sharing is a normal thing that happens in remote Aboriginal families, so someone who's got resources has to share those with everybody else. But it gets all mucked up if there's substance abuse or a gambling problem or some other issue of that nature. I think everybody out there experiences neglect.

I mean, an interesting thing for us was, that during the COVID period where the Centrelink pensions and benefits were increased by the Commonwealth Government because of COVID, we had a complete drop-off of the phone calls that we normally get every day about people not having enough food. Because everybody is trying to live on nothing yeah, everybody is experiencing neglect, but they're making the choice to live out there because connection to country is so important that people will put up with things that would be totally unacceptable to me, so that they have that capacity to continue living on country. Because the only other option is bring them in to Alice Springs or somewhere where they're hundreds if not thousands of miles away from everything that is important - family, someone who speaks your same language, access to cultural activities, being part of the community, that inclusiveness....”

NT Advocate, November 2020 Zoom workshop with DRC

“I have had some direct experience in a situation where a young man, eventually the day service got rid of him, basically. They just kept putting up barriers, raising his behaviour as an issue. So I would say that one of the challenges I think is day programs being resourced enough to be able to support individuals who present with complex needs, and particularly behaviours of concern, where there's a risk factor, so my cohort eventually end up not going and staying in whatever environment they're in, either at home or in a CRU [community residential unit] all day.”

VIC Advocate, February 2021 Zoom workshop with DRC

Examples – Trauma

“One of the biggest concerns we have is when child safety feel that they tick a box by removing a child, particularly from birth. They phone you to advocate for that person and they ask you to come to the hospital immediately. That is the situation which we find traumatic as advocates, let alone for the parents. There is no sense of recognition of trauma... being traumatised. No counselling offered or anything like this for people with a disability. As advocates we feel traumatised by that. The other scenario with that is, that because Child Safety have called us and we want to be there to support the person, sometimes that person with a disability can see you as a person that has helped remove that child. That doesn't help build a relationship when you want to try and help them, to support them to get better access to their child and everything else in the future. I don't know how everyone else feels, if they have had those scenarios as well. We have experienced that, even recently this year.”

QLD Advocate²¹⁷

“One [case] involved taking the mother right through the pregnancy and her making decisions about what she wanted up to the birth. Child protection had made the decision, they will deny it, but they had pretty much made the decision that the infant would be removed at birth. The experience of seeing it in a meeting room with the mother and social workers and nursing staff, although they were very caring towards her, they were telling her one thing, "You are doing a fantastic job and being a great mum." Yet she had no clue that they are going to remove this baby at all until the day she was to be discharged. Then the refusal to expand their decisions, to read through the documents, so that she can understand it, to the point where I had to say, "You need to simplify that. Explain it again so she understands." The child protection services seemed to think that was my job to explain their decisions and the reasoning behind it. I just kept saying 'You need to explain it, that's not my role.' I would remind them about human rights, discrimination, all those things. They would see that as a threat and would state that openly. "Don't you threaten us." In meetings, the meetings had three child protection officers, numerous nurses and two social workers from the hospital to confront this mother. Then she was told that she needed to go now, from here now, to the court to find out what is going to happen. It is quite brutal. We negotiated, and this woman has a moderate intellectual disability, we negotiated with her psychologist for some residential parenting courses. Multiple refusals to take her. Eventually one mainstream parenting program took her, but they refused to make reasonable adjustments, she has low literacy and numeracy... making marks on the baby's bottle, simple things like that. There was a refusal to do those things. This baby has been fortunate to be with the second foster parent, and has gone into permanent care of that foster parent. I raised very early from the start that to assess the baby and see whether the baby has any disability at all, because there were difficulties with feeding, or any other medical conditions. There was a refusal to do that. It wasn't until the foster parent, the court

²¹⁷ QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

order was ready for the foster parent to have permanent care, that it came to light that the baby... did have a disability which led to feeding difficulties. Yet in the mother's report, one of the reasons is that she lacked the skill to feed the baby and nearly choked the baby to death. A lot of this stuff. Now that is on record. This baby actually had major difficulties with feeding and the outcome for this parent is better than some. A minimum of four visits per year is the law, she achieved six with advocacy. Six access visits per year.

The way that everything was gone about, was totally wrong. Everyone noticed that she had difficulties with parenting, but with support... and no one was suggesting to leave a vulnerable baby.... But give her the opportunity to parent and put in those supports and systems. It was just a refusal, basically. It is pretty horrendous for all concerned."

"... the young parent I spoke about earlier, that was the basis of the infant being removed at birth, that the mother could not keep away abusive people. They were not offering any supports to help her in that respect and the mother herself had gone through Child Protection and they placed her in the environment that exposed her to predatory and exploitative people, and the things that have happened to her have been horrendous. So, it is often used and there was a VCAT-appointed guardian [Victorian Civil and Administrative Tribunal] in place for this mum, and it was difficult to keep some of these men away and some of their mothers away as well. The abuse was to the point that a mother and her son had decided that if he had a baby, they could get a baby bonus. They took this young woman and had her contraceptive device removed and promised her that they would look after the baby and she could live with them, and that was how she came to be pregnant, basically. It was very difficult to keep this mother... and we don't even know if he is the father, but that is one of the things that happened in the lead up to her becoming pregnant, and the violence was quite significant from a number of male perpetrators, including some of their female associates.

She became exposed to these people in the accommodation setting that Child Protection sent her to live at the age of 16. She was placed in an SRS [Supported Residential Service] prior to that age, and it is almost like they are ticking boxes and they have ticked the box and the resident is not their concern any more..."

VIC Advocate²¹⁸

"I have a client who actually WANTS to go into 2:1 SIL [Supported Independent Living]. She has experienced extreme trauma in the past and does not want 1:1 supports 24/7 because she is frightened to live alone with a support worker."

VIC Advocate, February 2021 Zoom workshop with DRC

²¹⁸ VIC Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

Examples – Restrictive Practices

“...there's a really insidious nature to restrictive practices and that's the language aspect of it. So what they say - if I had a dollar for every client that said to me - "Oh, that's the consequences, isn't it,...? The consequences is that I'm not allowed to do this, or I'm not allowed to do that, or I'm made to go to my bedroom", you know. So it's the insidious nature that really painting it as something else when it's actually a restrictive practice. For example, a client who drank the coffee, you know, and is not supposed to drink coffee, so they drank coffee and they said, "Okay, the consequences of that now is that you're not going to [Self advocacy program] anymore." Well, that's not a consequence of drinking coffee. The consequence is that you might be sick from drinking it or there might be no coffee left, but they're using it as a punishment. So clients don't understand the difference between what is punishment or what's restrictive practice and, you know, what's a consequence. But certainly, there are a lot of providers who use the intricacies of language to paint it as something else.”

TAS Advocate, November 2020 Zoom workshop with DRC

“a service provider sedates a client of a Community Residential Unit at 7pm each evening, despite evidence that the client needs high intensity exercise each day in order to settle at night. Support workers in the house are unable to support him with his exercise needs due to staff ratios. There seems to be little consideration at any level for the health effects of daily sedation on clients. The NDIS must raise the expectations of service providers about the level of support that should be provided in order to eliminate the need for restrictive practices.”

VIC Advocate²¹⁹

“People who are subject to RPs [restrictive practices] often report feelings of violation, fear, unhappiness, anger and sadness. They often report to advocates that the restrictions do not solve the problem of their behaviours, and that having greater access to freedom and decision making (and self-determination) would be more effective. Advocates often find that when a person is subject to RPs, there is an enormous focus on managing risk and providing treatment, but very little focus or creativity in supporting the person to have a better life, and to make more decisions themselves. Some people who have been subject to RPs for many years appear to be acquiescent and no longer protest against the actual restrictions. When they do present a 'behaviour' it is then immediately pathologised because the person does not appear to have any problem with the restrictions. Because support work can often look like baby sitting, it is very difficult to find members of a care team who will take the initiative to suggest activities with clients.

I have one client whose support staff take him to the bank to withdraw money, to cafes and fast food outlets, to buy cigarettes and to necessary appointments. His Behaviour Support

²¹⁹ DANA's 2015 Quality and Safeguards survey - Response from VIC Advocate

Practitioner often suggests activities he could try, but unless she really pushes, staff do not take up these ideas. This leads to the client feeling like his life is meaningless and restricted. When he feels like he is being controlled and has a meaningless life, he lights fires in protest. Support staff focus on strategies to prevent him from lighting fires and self harming, but pay very little attention to what gives him meaning and pleasure in life. This client is incredibly fearful of speaking up because past experience has taught him that it is not safe to do so (he has been regularly assaulted by family members and was assaulted by a staff member in a group home in 2019). People have not believed his reports of assaults historically and so he appears very compliant and acquiescent.”

VIC Advocate²²⁰

“I think that's a very difficult one because you've got to balance duty of care versus dignity of risk, and that's a very difficult thing to do, especially when you're dealing with guardians and administrators who would generally err on the side of caution when working with a client so that they'll generally try to keep the client safe and stable, rather than acquiesce to their desires and wishes, which they should within their rights be able to do.

For example, like a bloke that I worked with under a guardianship and administration order was, he was denied access to all of his finances just because the guardian administrator thought that he would go out and purchase copious amounts of alcohol and drink himself into a stupor, where like any regular person who's not under a guardianship order would be able to go and do that of their own free will. This person here was denied all of that and access to his finances to even make other purchases outside of alcohol or to buy gifts for his children or gifts for his family and, yeah, just because they were so scared of this person going out and kind of drinking himself into a state, that they just completely limited his freedom by cutting off his finances directly.”

TAS Advocate, November 2020 Zoom workshop with DRC

“Certainly we've had a bit of a trend... because the people we service don't often have many people in their lives, so are often appointed a public guardian, and I've noticed a real trend recently with the public guardian's authority over all sorts of ridiculous things. So we had a person recently be arrested because she went to see her boyfriend at his house, even though she spends three days a week with him. She went on a different day, so the guardian sent the police to come around and arrest her.

This poor girl was absolutely petrified. It's nothing to do with her guardian, her guardian obviously wants nothing to do with her either because she's made no effort in obtaining any of her choices, or taking into account this longstanding relationship that's been going for over

²²⁰ DANA's 2020 Restrictive Practices survey, Response from VIC Advocate

20 years. So I don't know, I don't know whether there's this extra power that's existing at the moment.

So that's been a real trend with a lot of the people that we service, being appointed guardians, being appointed for whole-of-life decisions, not just important things that are supposed to be decided on at the time, like accommodation or crisis applications, and they don't ever seem to go away. They seem to just roll over year after year with no thought into why that needs to be."

TAS Advocate, November 2020 Zoom workshop with DRC

"The person that I was working with most recently with restrictive practices, they were on increasing levels of medication, and they had a new provider who decided to put huge amounts of wood ...around their kitchen so that he couldn't actually access the kitchen unless staff wanted him to. And he had an acquired brain injury, and really had little understanding as to why that was happening, and certainly wouldn't have understood the reasons for his increasing levels of medication. And, therefore, he wouldn't have been able to - and he was nonverbal - so he wouldn't have been able to question why that was happening or to provide any response for that at all.

I think it had been provided over the years by multiple different psychiatrists and it had just been added to by the next one that they saw or by the GP in response to the service requests regarding his behaviour. Once he was moved out of that service and he was connected with one psychiatrist, the level of medication was reduced considerably and also he was moved to a service who - there have been cases of him eating inappropriate materials from the kitchen, which is why the service had closed the kitchen area - but with the new service they left the kitchen completely open and the fridge open and through discussions with him, and obviously dangerous materials weren't put in the kitchen, like bleach or whatever, but everything else was left open and safe. There wasn't stuff left that wasn't safe in the kitchen, but he had access to his whole house.

So, yeah, it was a change in service, or a couple of changes in services, that eventually led to his medications being really radically reduced, and also to the restrictive practices being removed in terms of access to the kitchen.

It involved [our advocacy organisation] for two changes in service, until that was got right, and the first removal of service resulted because they couldn't find anywhere appropriate for him to go, ...and then we had to advocate for him to come back from there and then for a further change for him to be close to his family. And eventually he had a good service and a home through Department of Housing, so that was another thing that we did so that then he could be more flexible in terms of the service provider he had. He didn't have to have a service that provided accommodation. And then, so yes, so that was accommodation through housing, which meant he could get a good service provider and advocacy for connection to

a private psychiatrist that bulk billed. So then he didn't have to have the continual changeover in psychiatrist from Department of Health he had had previously, where people stay six months and then moved on, or whatever. He now has a long term psychiatrist who's been working with him for, I don't know, three or four years now... has a complete overview of the medication he's on."

QLD Advocate, December 2020 Zoom workshop with DRC

"If I think about an example we've been looking at this week, it's multiple factors. It's organisations just doing what they've always done and not really changing the way they think about things. It's overestimation of risk. It's a failure of Quality and Safeguards to respond not only in a timely manner but in this case at all.

So we're talking about somebody whose original complaint was that during the COVID lockdown in regional Victoria, so he's in regional, lockdown was Melbourne, he wasn't allowed to do his usual community access. The reason given was COVID, but that didn't apply in the area where he was. He could see other people doing exactly what it was he wanted to do and was told, "Well, there's too many people doing it, so you can't do it." So effectively, "The rest of the community is going, therefore it's too risky for you to go", which makes no sense at all. A complaint was made to Quality and Safeguards Commission. That's eight months, six months, eight months and nothing.

So the service provider believes fully that they are in the right because nothing ever happened. Our client feels like, well, there's no point even complaining about it because nobody does anything.

I went to visit and there's a gate running along the side of the property which is closed all day every day so that there's no visibility out on to the street. He asks to have the gate open. The reason why the gate is closed is privacy, security, all these words are thrown around, but they don't actually mean anything. The only person who is at home in the residence wants the gate open. Why can't the gate be open? They don't have space in the house to do their personal hobbies, so everything is locked in a shed. They each have a designated area in the shed. That's where they go and do their thing, whether it's craft or whatever.

That shed is locked. They can't get into that shed when they want to. They have to ask a staff member and if that staff member says, "I'm busy", then they can't access it.

All of these restrictions are just treated as absolutely normal and any complaint made about them goes nowhere. So when you're talking about the higher levels of restrictions, the medications and the locked rooms, if you think it's normal to stop somebody accessing a part of their house or seeing outside on to the street or going where everyone else in the community is going, it's not such a big leap to think the other things are normal as well.

This individual also had an issue where an appointment needed to be rescheduled, a medical appointment, a very low-level, non-urgent medical appointment, and when an advocate attempted to assist him to call the clinic to reschedule, they actually said they won't speak to him because his "carers" (translation - support staff) from the house, make his appointments and they get to have a say about when he has his appointment.

If you can't even make your own medical appointment, how do you get to have a say in what medication you're given? How is that doctor respecting your rights as an individual to make your own choices? That just tells me that that medical practice understands that the service provider has complete and absolute control over this person's choices, which is just not true."

VIC Advocate, February 2021 Zoom workshop with DRC

"I actually had a support worker give me a call... So they worked in a group home, and they had been told by the company, the group home manager, that nobody was allowed to spend money more than two coffees a week. Previously they'd been going out for meals on Friday evening, but because of COVID, they weren't allowed to go shopping, they weren't able to go out for meals. In fact, there was no cash allowed in the house. The only money in the house was on the credit card held by the house manager. I support one of the men in the house. His parents gave him a house as part of his inheritance, and he gets rental income from that house. He actually works for the ADE [Australian disability enterprise] of the accommodation provider and so he's working for them and he's supposedly getting a pay cheque from them. He also has his NDIS money. And he's being told, "No, you can't go out for a meal; no, you can't go shopping because you don't have any money." So even though this man is obviously entitled to be getting income, he's being told he can't have any access to money. I was talking with the support worker and he says "What can I do? I can't go to the police because the police want evidence." I said, "Go to the Ageing and Disability Commissioner and definitely talk to the Disability Royal Commission." Then at the end of the phone call, I went how does this actually work? And I rang the abuse hotline, the Ageing and Disability Abuse hotline, which I'd referred the guy to, and they said, "Oh, is this service provider NDIS funded?" and I said yes. And they said, "Oh, we can't do anything. You need to ring the Quality and Safeguards Commission". OK, so I rang the Quality and Safeguards Commission. "Oh, is it about money? No, we can't help you at all. You need to ring the fraud hotline." So I rang the fraud hotline and they said, "Yes, this is the right place to report it. I just need to let you know that we can't give you any information about any investigation that we do or even if we are going to do an investigation, for confidentiality reasons." And then they said, "So can we have your phone number and email address?" So I said, "You're not actually ever going to give me anything?", "No, no, no, we can't give you anything." So there seemed to be no relevant reporting and accountability structure around this thing, this matter of financial [restriction] which wouldn't just refer to one resident but potentially would refer to all the residents in that particular organisation."

“...we didn't talk today at all about restrictive practices in the family home. It's not an area that I have much experience in, but I would be interested to hear from anyone who does. I have had clients who certainly have had issues around family members trying to take control of their finances.”

NSW Advocate, March 2021 Zoom workshop with DRC

“In terms of financial abuse, I have had circumstances ... where independent people are living in supported accommodation and have been told that they need to give access to their cards to service providers to get them things like clothes, and although the financial guardian has been involved and has told them to send the invoices to them, the service providers don't want to do that. They see it as a bit of a hassle...”

NSW Advocate, March 2021 Zoom workshop with DRC

Examples – Failures of accountability

“...it is very challenging. If I look at our supported residential service in Victoria, the SRS [Supported Residential Services] sector, like boarding housing in NSW, for-profit businesses, often there are rumours and reports of sexual abuse, proprietors, and not every SRS is like this, but the unscrupulous ones, where there are proprietors or managers with predatory behaviour, we find out way too late. Way too late into the matter. To the point that the person with disability is fundamentally denied access to justice. Police will not pursue a matter if they don't feel it has merit and that they can't get it up to a certain line with the evidence they need, beyond reasonable doubt.

I had one young woman who had reported sexual abuse to police, but we didn't find out until many years later what had happened. The Department of Health and Human Services are the regulators in terms of the authorised officers to go in and see that the SRS is complying. But often when we have complained about things, they are advocating for the SRS provider, as opposed to being independent and impartial. I've raised complaints and they've said 'well, we'll just have to see what they see it as'.

Complaints go nowhere. So there is a difficulty in a sector of accommodation that is not part of the NDIS. When I eventually went to the police with this young woman, because she made a disclosure to me, she had inferred things before, but on this occasion after building trust with her, she made a disclosure. I went to the sexual offenders unit of the police and reported that... that is when I found out they had received a report of this many years earlier and they were not going to pursue it. And they were not going to reopen it because that SRS has been closed by the Department.

The Department closed the SRS because of rumours and innuendo, and yet this woman has made allegations of a horrific assault and nothing has happened. We are finding out way too late, and there is far more of this happening, out there.

I'm hearing SRS proprietors where... this is not sexual abuse alone, there is financial abuse of SRS proprietors who have a business on the side, such as a warehouse where they are packing, and they are taking residents with disability to work in that factory, for nothing.

When we raise it, nothing is ever done with it. It's wrapped up as 'we are going to go on a special outing for you, and you are going to get things and you are going to wrap these things and it is going to be fun', but they are an unpaid labour force, people with a disability that often don't have anybody else in their life in terms of informal supports.

There's a whole lot of stuff happening out there, and they are not clear pathways of getting something done about this. We try to make noise about this, try to do things about it, but it goes nowhere.”

“Could I just add, in terms of the Supported Residential Service sector, the for-profit boarding house type of accommodation, what concerns me is the interface between DHHS [Department of Health and Human Services, Government of Victoria] and their role as authorised officers, so they are making sure that these services are compliant with regulations.

Now, what we will often hear, this is a systemic issue, in that when there is not any other accommodation, this is where people with a disability often end up living. Not just people with a disability, a broad range of people in our community end up living in an SRS.

Now, a case in point is that there is one that is about to close. There is one that has closed recently, another two about to close... Suddenly, the Department of Health and Human Services who are the authority that regulates, have en masse homelessness issues for these residents. More often than not, it's something that they have to pick up.

So there is a real conflict that the Department will have the financial responsibility in some cases, but also the resources of finding accommodation for 30 residents at a time. So maybe it's the cynic in me, but it seems they turn a blind eye to certain things, because otherwise the problem becomes theirs... to manage and find accommodation for people.

But where does that leave vulnerable people living in this kind of accommodation, when we know things are happening that shouldn't be happening at all, and the person regulating has a conflict? Because they are responsible for making sure of compliance, but when it goes wrong, they are financially responsible for finding alternative accommodation for these residents. It is a real conflict, and I think it needs to be addressed. I'm not sure about how it works in other states, but it is a problem.”

VIC Advocate²²¹

²²¹ VIC Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

"I think consequences for service providers around using unauthorised restrictive practices because they seem, I know I've worked on a case, the senior practitioner said, "You've got two weeks", because there's been complaints put in about unauthorised restrictive practices. "You've got two weeks to provide details to me," and it was eight weeks later before they provided the details to the senior practitioner. So the organisation thought they have law of their own to do whatever they like, and they've taken away from this person having things that were dear to her, or having milkshakes, with no justification and it's like they were fined, or something like that, I don't know, but there was no consequence for it. They just did everything in their own time."

TAS Advocate, November 2020 Zoom workshop with DRC

Examples – Co-design

"A woman who had CP [Cerebral palsy] and high support needs, complained to the hospital via an advocate about neglect and discrimination, as the nurses failed to ensure she had drinks and food. They placed everything beside her, but she couldn't do anything without assistance due to her CP. Her nominated resolution was to offer a training course for hospital staff about people with CP. The hospital agreed and together we designed the two-hour course. The evaluations were fantastic from the 40 staff who attended. Most said they'd never thought things through before and this was one of the most 'authentic' courses ever! My client was thrilled at the outcome of her complaint. I know she'll be far more assertive at her next hospital stay or ask for advocacy assistance."

VIC Advocate²²²

Example – Creatively exploring causes of "behaviour"

"It is about culture and training. This is prior to NDIA being in effect, but there was a young woman who had significant behavioural problems, who was banned from a program because of violent outbursts, grabbing people and shoving them up by their throats against the wall. Moments of despair, sleeping during the day, up and active during the night. There was pressure in the house from other families, because this young woman would pull people out of their beds, things like that. It was a significant impact and there were specialist services involved, but no one was making progress until we got... we used a care team approach.

She was at the point of ending a notice to vacate. So she would have gone from a group home that she lived in for many years, into a house that the department would have pulled out of mothballs. She would have lived all by herself with four other staff coming and going. No other support, no ability to socialise with peers, etc. We took a care team approach, brought in a specialist speech therapist for people with little or no speech. We did a full health

²²² DANA's 2015 Quality and Safeguards survey - Response from VIC Advocate

check from psychiatric to physiological. Really honing in on all of those things to see what the triggers were.

It ended up that she was melatonin deficient... which was causing all of this behaviour. But the biggest thing that really worked was the speech therapist that came in and basically, what we needed on the ground to lead a change management approach as to what was happening, and the house supervisor put up his hand and said he was willing to lead it. A lot of the staff were afraid to say that they were burnt out, that it was difficult for them, none of them would speak up, but the team leader stepped up and said he would lead this thing.

It involved staff being trained in communicating and were filmed communicating with her. You could see these micro moments of where they had missed communication, full stop. That communication training – those videos became part of training when working with this person. We had a funded iPad and it changed everything around, together with the melatonin being administered. She went from being right on the cusp of being moved out of the property within days to she is still living there now. So, things can change, but then there needs to be someone in that setting who will say they will lead with this. And they will back the staff up and they will get them all on board by leading the way. If you don't have that, people are afraid to put their hand up and say 'I can't do this,' or 'this is too hard.' or they don't want to acknowledge that something is too hard because they don't want to look as if they are incompetent. But, they were dealing with something that was very difficult and extreme. There are good practices out there, but it takes a lot of work to get people on board, a lot of effort. I think that all of those things need to be checked off before any person with a disability is vacated from their home. And looking outside the box, they were all looking at sensory issues. Whereas this was a medical issue. She was terribly chronically deficient, and it caused long-term psychiatric behaviour.

...My initial role was to prevent... to delay – use delay as a tactic to stop her being moved out ... I liaised with her family because her mum is her only surviving relative. An elderly woman. I liaised with her. I got a lot of history, trauma events, any of those types of things. I went through all of the house records, what were they doing in terms of communication, were staff doing things? I looked at her room to see if there was – what was about her room... her room was stripped bare, there was nothing in there, she would pull things to pieces.

What led to the melatonin deficiency, I noticed that her bedroom light was on, old-fashioned fluorescent lights, and I said why is the light on? And they said, you can't turn it off because she'll have a panic attack if there's any darkness. So it was creative detective work. The department brought us in, because if someone gets a notice to vacate, they need to bring an advocate in. But this had been going on for two years before there was an advocate. That is another issue. They had to get an advocate because there was a notice to vacate.

It really was facilitating a change management approach, looking at what had been done, what worked, what didn't work, and then... suggesting that you need a communication assessment, 'when was the last communication assessment done?'. Just going back through

those things and taking the issue away from it just being sensory. Behaviour is trying to tell us something, what is causing – why is someone behaving like this? The advocacy was to uphold her rights, keep her in her home and do the detective work that was needed to get people to do their job. That did involve supporting people to do their job, acknowledging that this was a hard and challenging circumstances, but let's try these avenues. Whilst the avenues were being tried, they could not vacate, they could not exit her from the house.

It was to use all of those strategies. And once everything was put in place and they could see behaviour changing - there was rapid change in behaviour - and there was no need for advocacy then.”

VIC Advocate²²³

Examples – Positive change in services and systems

“...a smaller example, but it only happened in the last two weeks so it's on my mind, is that I became an advocate for a young lady living in a group home in her mid 20s who was living with three other co-residents, all aged under 30, and I would go around there sometimes to visit her on my way home from the office, so at 5pm, and they would all be in their pyjamas, having their dinner at 5 o'clock, having already been showered and wearing their pyjamas. I started speaking to the house manager about the fact that the young lady I am advocate for would like to go out for dinner, would like to attend a restaurant, go out for dinner with some friends and socialise during the week and not be in bed at 6.30pm. So they have now introduced twice-weekly dinners for the co-residents to go out in the community and have dinner together. That is a small example but it's a significant one for those ladies. They have all spoken to me separately about what a joy that is for them now and how much they're looking forward to that.”

NSW Advocate, March 2021 Zoom workshop with DRC

“It's a case study of a woman probably now well passed away actually. When I was in my 20s, I was a residential care worker and this was in New Zealand, but I am a sure it will be the same here. There was deinstitutionalisation, so people who had lived in institutions since they were 5 or 6 or 7 were now suddenly living in group homes and going on trips in the community and going to supermarkets. Things that they hadn't ever done. And they were medicated to the eyeballs. They were on all sorts of temazepam and all those sort of high-level medications.

Of course, initially when they came out into the community and those medications were reduced, there were a whole lot of things. We didn't know that you could call those things behaviours of concern and challenging behaviours and all that. I mean, they just were how

²²³ VIC Advocate, "Advocates Zoom In On... Safeguarding rights and wellbeing", December 2020 Zoom discussion

they were when they weren't drugged up. It's probably why they got young 20-year-olds to look after them.

We would race after them, and we had to learn various different sorts of strategies and we had to do specific training about how to work with these people. And over a period of, sure, a few years, those people who were nonverbal, who had never had any experience from their childhood, and these individuals we were working with were in their 40s, they had been institutionalised for a very long time, they were going to supermarkets and putting things they wanted in the trolley with the support worker. They were contributing in the kitchen and helping prepare their own meals. They were electing what things that they wanted to do, even though they weren't verbal, they would use cards and other mechanisms, and you go from an extreme where a person's reaction in the first week of her again, the specific woman, the first week of her release into the community, she bit my arm. I mean, she was half my height, but she bit my arm, and also head butted me, so she was obviously quite experienced at defending herself, and she went from those behaviours, and then just was really intensive stuff, training and just guiding her, she eventually trusted her environment. All of those behaviours vanished. And she was able to live in the community and have a really happy and enjoyable, it seemed, from what I saw, life.

NSW Advocate, March 2021 Zoom workshop with DRC

“... there is one example in particular...[at a] primary school. We had a family member there whose daughter was forced into the support unit and the mum advocated really hard to get her into the regular classroom. After a period of time, not only did the teachers realise that it was working really well with good practice, that the principal started to see that as well and it ended up, it's ended up in that school that all the support units are now starting to - I won't use the word be dismantled - but they're starting a movement called Collaborative Classrooms.

So they're trying to ensure that there's a lot more proper engagement and inclusion with all children, so the children with disability are actually engaging with everybody and not just when it's the music class, and then they pull them in, and then they pull them out. So that's had an impact in a systemic way and in a really positive way.”

NSW Advocate, March 2021 Zoom workshop with DRC

“I have recently been working with a service provider who has performed beautifully in improving their practices and that is to work as an absolute part of a team with the advocate, the mother, the family, the support coordinator and another service provider that's working jointly. We work as a team together. Everyone is on the email list, including the family, and we have stakeholder meetings every two weeks and all incident reports are shared with the family and the service and everyone works together in discussing approaches and strategies within the... (inaudible) provider who is willing to include the advocacy as well as everyone.

...I [initiated bringing together all of those players]. I worked very hard. I think people are a little bit frightened when you talk about transparency and openness, but there was a level of trust and it has been happening. We have a very good support coordinator, who's very highly experienced, and everybody just commits to it and it's just the first time that this man has had a service, the longest that he's had it, you know. Usually services end in five weeks. For him he's had a history of failed services, but this time it was implemented very well.

...They have recognised that that's a good way to manage their things and I do have them with another service and they're very willing and open to doing the same thing with another person that they are providing that service to."

QLD Advocate, April 2021 Solutions focused workshop with DRC

"...there was one I think is noteworthy and that's a very small organisation who I think do much better jobs. They changed their service agreement based on feedback from one participant. I think that was a really positive thing that they did.... They're a boutique model of support and, yeah, I think they're very responsive."

SA Advocate, April 2021 Solutions focused workshop with DRC

"[Our organisation's] Advocates have had similar experiences with small new NDIS providers. Not the same experience with large providers."

QLD Advocate, April 2021 Solutions focused workshop with DRC

"...boutique services appear to be more likely to consider change. Large services demonstrate significant resistance to changing policy and practice.....they prefer the person to change, and if they don't, the service asks for positive behaviour support plans."

SA Advocate, April 2021 Solutions focused workshop with DRC

"Some new organisations have emerged since the NDIS started in NT and we have found them to be much more person centred and flexible in their approach to providing services for people with disability"

NT Advocate, April 2021 Solutions focused workshop with DRC

"As far as the quality of support workers that are being employed by service providers, it's quite questionable. And a lot of them have got no experience whatsoever, and then they will pair them up with someone with really high needs and intellectual disability and expect that person to be able to cope with the person with high needs and of course it's going to fail. Then that poor person with the disability is left with no supports. And that's a common theme

in this area, there's a shortage of support workers, so I'm finding that they're employing people who really shouldn't be working with people with disabilities. Who's there to speak up for that poor person with disabilities?

So I think better training, and sometimes these organisations can be proactive. There is one I know of up here who actually... because I've spoken to them and told them about this situation and it was sort of a cultural thing in their organisation, and also the staff, their admin staff weren't very nice to people with disabilities either and... told them they can't choose the workers they want to work with, et cetera. Those people have been dismissed, which is good.

So there was a bit of a cultural thing in that particular organisation, but the CEO has... there's been a new CEO employed and she's looked and gone no, there's a bit of toxic admin staff here or people that are not respecting the choices of people with disability, so she's actually got rid of them, which I thought was really good. So these services can make changes, but it has to be brought to the attention of the person at the top, the CEO or the managers or whatever, to make changes. They need to make sure they hire quality staff, at least train their staff before they put them with someone with the high needs so they're not put at risk.”

NSW Advocate, April 2021 Solutions focused workshop with DRC

“...I've seen a situation where they've just changed the processes for that one particular person because we were working with the participant and we work with people with intellectual disabilities. But I've also seen just recently where a provider has gone out of their way for one incident that happened, and changed their policies and procedures and even their training. I think the barrier there is just the willingness to do it, so one provider wasn't really willing to dedicate resources to ensuring that their processes are adequate for their participants, whereas another one just was able to do that.”

“...they're a nursing provider that there was a big medication mishap which ended up with the person with disability needing hospitalisation, and quite serious hospitalisation and they... yeah, they just identified, you know... they basically confirmed what we found in our investigation as well, but they also found out that initially it was definitely an issue with their policies and procedures, and also particularly their policies and procedures didn't really... it was very difficult for a new person to come on board, like a new employee to come on board and follow those procedures. So they went back to the drawing board, from what we can tell, to realign, yeah, their procedures to make it more accessible to everyone in the organisation. They even went to the point where they allocated for each person... allocated a manager that needs to do at least two shifts with the participant in the week.”

“...The previous one actually walked away from this person because it was a little bit... this person had complex needs and was probably a little bit too difficult for that other nursing provider to deal with. So yeah, it probably depends on the provider.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

"...one thing on providers we've had good experience with ... I'd say [WA provider] is one. You know, we've seen a good transparency around their operations of being supportive of advocates. The other advocates access to information like NDIS plan provisions and plans."

WA Advocate, April 2021 Solutions focused workshop with DRC

Examples – Community participation

"I just want to tell a little story which might give a bit of an idea. So this is a young man who lives in a... just an ordinary community, suburban community, but he's been very present in his community through school, through Scouts, through lots of different experience. So he was a Cub, he was a Scout, Venturer, he was just a part of his ordinary community.

He doesn't have a depth of relationships with people, but he is very well known and he's got a very supportive family and has a very, very strong relationship with his mother, but on a particular occasion that his mother didn't know about until sometime later, he had been at his home and there had been a commotion outside. He had gone outside and intervened in what was a domestic violence thing that was happening, and there was a man and two women and he tried to intervene to say for the bloke not to be assaulting the woman, and for this other woman who was also being really abusive.

What happened was that... tragically, one of the women hit him. She kind hit him. She punched him and he was injured by that. What he did was not go back into his house, but he went immediately to his local supermarket, where he was very well known, and the workers in that supermarket called the police, sorry, called the ambulance and they stayed with him until all of that had happened and got him home and that had nothing to do with support services or close friends or family, because he had a feeling that what he had done was he'd put himself into a risky situation, and so he was a bit concerned about telling his family. But that's what happens when you have somebody who lives their life in community.

The other thing that happened was that he went to the local pub to the drive-through thing and the guy that worked in the pub knew him and knew his neighbour. He rang the neighbour and he said, "Oh, Fred's here. What should I do?" The neighbour said, "Do your bloody job." So, again, it was another aspect of this is really ordinary life, and that he had people in his life that knew about him, and knew him much more intimately in the fact that it was a community that knew him.

So it was, this is what we need to be happening for people, and you all know about what happened to Ann Marie Smith here in South Australia and this could have been prevented. All of those safeguards that we talk about, and people have talked about, you know, all of that stuff that happens with service providers...it's actually a local community that's going to keep you safe and so people say, "How are you?", "How are you doing?" Or if they see somebody in distress that they know, they will step up. They're not necessarily saying, "Come

home and have dinner with me", but they see you in the street and they know you, and so they say... local cafe has a bloke that comes in, you know, he's homeless and he's got a mental illness and every week he goes in there and they just give him a drink. He's known there and they don't shoo him out the door, they invite him in, "Sit down, here's a drink, here's food, how are you doing this week, see you next week." That's what happens in ordinary community."

SA Advocate, April 2021 Solutions focused workshop with DRC

Appendix A: Advocates voice their ideas for improvement

"Family members need to formally be recognised as important voices in people's lives. This needs to be formally recognised in policy.

Segregated settings need to be placed at the heart of communities rather than at the fringes.

Great care should be taken to ensure negative images are counter-balanced rather than reinforced.

Quality settings should be evaluated in terms of continual improvement towards least restrictive and least secluded practices.

Socially valued roles should be increasingly sought and celebrated."

NSW Advocate²²⁴

"...there are vehicles there, that can be used and developed and amended and expanded on that can really help in this space, I believe. We need some of those focuses, that we discussed as a group in this forum, are really important that we elaborate and they go back to training of people who work with people with disability. Making sure that people with disability, carers and families and advocates know what restrictive practices are and what they can do. What are the alternatives that are rights focused and that move away from these practices that are really outdated and can be quite abusive. Making sure that the training that we implement here in the ACT is relevant and is rights focused and doesn't just happen at one level, but happens regularly throughout the person's professional life. And making sure that the information is out there so that people know the role of the official visitor. The role of advocates, how they can be contacted and that more visits take place with the official visitor so they're aware of what's going on."

ACT Advocate, October 2020 Zoom workshop with DRC

²²⁴ DANA's 2020 Segregated settings survey, Response from NSW Advocate

“independent vigorous ample advocacy [organisations], more community visitors and independent watchdog with some teeth; office of public guardians who advocate for clients and protect their interests rather than rubber stamping poor practices in field which is current situation in NSW”

NSW Advocate²²⁵

“When people with disability, their families and carers, encounter an issue or barrier to accessing a service or program, or any other areas including access to health and medical services, transport and related infrastructure, equipment, aids and appliances, home modifications, vehicle modifications, et cetera, they should be encouraged to make a complaint ASAP to prevent it from continuing and simmering. If the person with disability, their family and carers are unable to get the issue addressed, or do not feel confident or are hesitant to make the complaint themselves, they should always be made aware of / encouraged to access an advocacy service. Ensuring the issues and barriers are addressed ASAP will enhance the safety and wellbeing of people with disability, and if the barrier or issue is addressed, it should ensure that these issues or barriers are removed and the quality of the service is improved. Not only for the person with disability, but potentially for all people with disability using those services or programs, transport, equipment, aids and appliances services and programs.”

SA Person with disability²²⁶

[The use of restrictive practices can be prevented, avoided or minimised through:]

- *“Focus on capacity building to remove skills deficits;*
- *Person centred planning focusing on the individual’s strengths and goals;*
- *Comprehensive Health Assessment Plans so that health issues that may cause challenging behaviours can be identified;*
- *Better understanding of sensory triggers for challenging behaviours and adaption of environment to remove environmental triggers for behaviours.”*

“The QLD regime needs to be extended to fully cover people under 18, people in respite and people accessing community programs. OPG [Office of the Public Guardian] should be more willing to consult the person subject to an RP and their advocate (where relevant).”

QLD Advocate²²⁷

²²⁵ DANA's 2015 *Quality and Safeguards* survey - Response from NSW Advocate

²²⁶ DANA's 2015 *Quality and Safeguards* survey - Response from SA Person with disability

²²⁷ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

“Clients need to be provided with an easily accessed, clear and meaningful way to speak about what they need and want. This voice must be considered as the fundamental core that all actions are accountable to.”

Supported decision making needs to be formally established as best practice and legally recognised.”

QLD Advocate²²⁸

“The Disability Discrimination Act needs to be reviewed.”

NSW Advocate, March 2021 Zoom workshop with DRC

“I think also to make people aware and strengthen the role of the Official Visitors Scheme, we have had a number of referrals through them for advocacy support.”

ACT Advocate, October 2020 Zoom workshop with DRC

“Legislative, policy and cultural focus on:

- *human/disability rights quality of life and opportunities person centred planning and disability practice funding for supported decision making and other safeguarding mechanisms in NDIS plans;*
- *training and knowledge transfer about state and federal interfaces;*
- *greater focus and policy development within NDIA and organisations on good lives rather than 'therapies';*
- *greater transparency about how the QSC handle complaints and what factors they consider;*
- *greater opportunities for training for all disability sector staff - so that anyone who works in the sector is able to easily identify a restrictive practice (RP), and understands why someone might be subject to RPs;*
- *better funding for support around RPs - therapy assistance, greater training of support workers, greater funding for care team meetings, introducing case management (on top of or instead of support coordination).”*

VIC Advocate²²⁹

“...the community visiting scheme if there was some scope for people living in private settings to have access to that and again, you're always going to need someone to alert those services or something and that's always going to be tricky, but if there was some regular

²²⁸ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

²²⁹ DANA's 2020 *Restrictive Practices* survey, Response from VIC Advocate

service that could go and just do a check on people living in those types of situations, it might be able to assist those people to access supports that they need to ensure that they're not living with restrictive practices."

SA Advocate, December 2020 Zoom workshop with DRC

"having a campaign that highlights the rights of all people with disability and includes restrictive practice being exposed".

VIC Advocate, February 2021 Zoom workshop with DRC

"It's been flagged before... Community Visitors Scheme being introduced to Tasmania. ... I think it would be a useful thing, you know, particularly we see people who don't have any family or friends involved in their life, and they're often the people that aren't, when restrictive practices are placed upon them, it isn't noticed because nobody is looking out for them. So I think a community visitor scheme would be an extra benefit to know that people are going in and keeping an eye out on vulnerable people that are isolated."

TAS Advocate, November 2020 Zoom workshop with DRC

"I think in the absence of a really well resourced, independent advocacy sector, we've got to see more community visitors, people that can come in unannounced any time and look at the conditions in that particular setting and ask about restrictive practices. I think the problem with the current practice with community visitors is that they're almost, not saying toothless tigers, they're more kind of in the pocket of some of the providers, they don't want to get too controversial and providers can work them, gain them. I think that needs to be beefed up. There needs to be more of them, and they need to be going hard if they have to.

And part and parcel with the lack of resourcing with community visitors, is the lack of resourcing of independent advocates to come in. And I'm not talking about our model, but anybody who needs an independent advocate should be able to get one. It's just not possible now to follow things through, particularly with the Office of the Public Guardian overseeing a lot of these clients, but not on the spot. They might visit them once a year or twice if they're lucky.

In [QLD city], people rarely see their decision maker from the Office of the Public Guardian because they don't have the staff and they don't have the budget, so they rely on community visitors. I believe there needs to be a lot more effort put into monitoring these settings because there's going to be more and more of them as money pours in through the NDIS."

QLD Advocate, December 2020 Zoom workshop with DRC

"I just wanted to throw out there that with Worksafe, they have penalties. I think there needs to be sharp and very severe penalties because what the service providers are doing are saying, "Oh, yes, okay, we're going to fix all of this stuff", but nothing happens, nothing changes, it's just all words. Actions speak louder than words and honestly, there is no law against, unless someone actually dies, and this is what I've been told as well by the Commission., unless someone is actually, someone dies. We do not want another case like Ann Marie Smith, we do not want another case like that. I'm sorry, there's going to be more and more of those because there's no protection and no safeguarding for these people."

VIC Advocate, February 2021 Zoom workshop with DRC

"Family members need to be formally recognised as important voices in people's lives. This needs to be formally recognised in policy."

NSW Advocate, March 2021 Zoom workshop with DRC

"I would hope that the DRC report at the end of its term would be very firm on actually realising the CRPD [United Nations Convention on the Rights of Persons with Disabilities], and the National Disability Strategy, that must have clear implementation procedures, and we need a national human rights act."

QLD Advocate, December 2020 Zoom workshop with DRC

"in the past I worked in apprenticeships and what we had in apprenticeships in Victoria was what was called the 'apprenticeship field officers'. These apprenticeship field officers had very good powers, who were able to walk in to any employer's business, and demand to see payroll, working conditions, et cetera, et cetera. Whenever an apprenticeship field officer walked into an employer, this is for apprenticeships and trainees, you were jumped, the powers were quite great.

I would like to see something like that introduced, where we've got - I mean, we've got community visitors, but they just don't have the powers. I think we need people on the ground that can walk in at any time to any service provider and demand to see records and see how things are. It will be a cost, but I think that would help, and then at least then, they can see what's happening on the ground as well.

Now, those apprenticeship field officers back in the day were then able to go back and there was a list of banned employers, this is after investigation of course, banned employers or employers that when they took on an apprentice or trainee then had to have some consultation around taking on this person, what their requirements will be from an employer

and going to trade school and things like that. But the system worked really well. Again, it all comes down to funding. But something similar would work.”

VIC Advocate, February 2021 Zoom workshop with DRC

“...the reason why we're always banging on about inclusive education is we feel like that is the first step. We need to start with that because that will lead to gaining employment, which will lead to being able to afford housing, et cetera. So we are really wanting to have a strong focus on inclusive education. I understand that those issues are there with the boarding houses and I don't want to take away from that at all, but I really think we need to think about why are they there, and make sure that people with disability are part of our society, and belong to society, and are within it and not just being thrown funding to do activities and essentially time waste. What can they do to genuinely have employment, so what can we do about the great divide between education and employment? And in terms of having customised employment, and starting to really promote those models that are innovative and contemporary, so that we can, people with a disability can actually afford to make choices about where they live and who they live with, et cetera.”

NSW Advocate, March 2021 Zoom workshop with DRC

“I was just going to say, one of the things that we see all the time, is the lack of knowledge in health professionals, Centrelink and other organisations when people with disability are trying to access services, and it's about the outcomes that people with disability receive that depend on the knowledge of the particular practitioners that they're in contact with. And so having some consistent education across those institutions would be, is vital, and we see our role as getting that information out to those various providers.

Again, you can only do it sort of within the scope that you're able. So, yeah, an example of that is if someone is applying for NDIS supports but the doctor doesn't really understand what the NDIS require as evidence. We see that time and time again, where people are rejected because there's been a lack of proper input from the medical practitioner.”

SA Advocate, April 2021 Solutions focused workshop with DRC

“I think removing segregation across all systems, particularly education, housing, it's so important in this regard... divert from within the criminal justice system in a way that's appropriate, so we're not diverting people for a forensic disability system which indefinitely detains them in prison-like conditions, but therapeutic rehabilitation and habilitation ...”

QLD Advocate, April 2021 Solutions focused workshop with DRC

“...the way in which the Optional Protocol to the Convention against Torture is implemented is critical - we need dedicated legislation, mandatory reporting, obligations to the National Preventive Mechanisms, ensuring the inspection bodies are disability informed and aware.

There is also a need for the NDIS Q&S Commission to be redesigned to be independent, proactive.

... there is a need for a plan for sustainable advocacy funding, that properly reflects the role of the NDIS and the need for independent advocacy”.

QLD Advocate, April 2021 Solutions focused workshop with DRC

“...consistency of workers and time to be present to people with disability can be replicated across systems.”

SA Advocate, April 2021 Solutions focused workshop with DRC

*“... trauma informed practice training,
removing segregation in all settings but inclusive education is critical”*

NSW Advocate, April 2021 Solutions focused workshop with DRC

“From my perspective, firstly I'd like to see that there's almost a declaration that this is a crisis, this is something that needs to be addressed, the number of people with disability that are living in a situation or have been exposed to abuse, violence, exploitation.

The second thing I'd be pointing out is, what does the future look like, succinctly spell out the future, and it could have key elements in it... For example, that people with disability should be involved in all levels of decision making, and I'm particularly talking about people with cognitive disability here. There's some involvement of people with cognitive disability, but there needs to be a cultural and a community shift.

That there needs to be not only the exposure, because I think this is what we've done, I think we've exposed, we've talked about it, so now we need to set up systems that ensure transparency, which I think a few people have spoken about here, that transparency, that safeguarding.

I think COVID has been another example of all of this being exacerbated and for the most vulnerable people... and so that needs to be highlighted.

Then I suppose one of the last things is ensuring that we continue to declare or we continue to highlight the value of advocacy as a safeguard or an oversight measure, and it's a critical component... it's not an add-value, it's a critical component to the outcome of any recommendations.

This is a golden opportunity to change our future and I would not want to see this lost.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“I just wanted to go quickly back to the safeguarding issue. So I was thinking, advocacy is part of that nexus of the Quality and Safeguards Commission and lawyers who provide... have this safeguarding role, but one of the things that's really apparent, I suppose, in most legislation around Australia, although I guess I'm speaking more specifically about Victoria, is that people's rights don't travel with them across sectors and across legislation and so safeguarding doesn't either. So we have these pockets of people who are not able to... they don't have rights because they happen to be subject to legislation that is stronger than disability legislation, and so we have these kind of dark forgotten corners, like people in prison and people involved with child protection, for example, which are two really big areas for us at [our organisation].

So we actually need to have some legislative change around strengthening disability rights within legislation so that people's rights can travel with them because, at the moment, we basically have a system where you can only have rights in a disability system, you cannot have rights in any other system because the legislation in other systems is stronger.

So one of the things that we find in advocacy, particularly around child protection and people involved in the justice system, is that talking about disability rights, talking about the UNCRPD [United Nations Convention on the Rights of Persons with Disabilities] is fairly useless because it isn't... it's not enshrined in legislation, or it's only in disability-specific legislation. So we have to rely on, say, for example, the Equal Opportunity Act in Victoria, which we know is not strong. We also know that the human rights charter is not strong and has to be tied to other legislation.

So in advocacy, we can do what we want in terms of the NDIS Act, in Victoria the Disability Act, but once we have people who are trapped in other systems, we have absolutely no power. So we only ever serve people in disability systems... People with intellectual disability in particular, I guess, only have rights when they're in disability systems, which they're captured in, and when they go into other systems, they lose those rights. So then one of the things that happens is they bounce between systems, but it's usually a mess and there is no safeguarding for people when they're bouncing between different systems.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“...some of the things my team was saying are just visibility in pop culture, representation, and also early childhood education, and visibility and proper education for teachers in terms of inclusion, representation, staff training. I think those are the kind of broader population initiatives.

...I think one of the things that was mentioned when I was chatting with colleagues was that rarely are people with disability as actors in mainstream programs represented as fathers, lovers, whatever it might be... it's still often the case that it's about the disability. So I think that's starting to change, and it's not something you can just kind of change overnight or with the right policy or whatever, but I think these are the kinds of things that go a long way to progressing the culture."

VIC Advocate, April 2021 Solutions focused workshop with DRC

"...may include involving people with disability in decision making at all levels, including people choosing their own workforce in group homes. The culture around zero tolerance to abuse, restrictive practice. Valuing people with disability and their contribution in our community and society. Also a cultural change around the value and powers of advocates."

VIC Advocate, April 2021 Solutions focused workshop with DRC

"We must not forget about the abuse and discrimination occurring at the hands of some family members. Who has oversight or safeguards these people?"

... When the only option is a welfare check by the police, often people don't want to get the police involved, we need a Safeguards commission for people being cared for by family members.

...Strengthening the relationship between OPA and the advocates who are frontline?"

VIC Advocates, April 2021 Solutions focused workshop with DRC

- *"Accountabilities from those service providers that have had a complaint against them or several;*
- *Penalties to those that show neglect and abuse but aren't serious enough to charge;*
- *More regular but random audits that include the people who use the service – unannounced;*
- *More protections for those that make a complaint or are whistle-blowers, in particular with the employer, so people don't feel uncomfortable or don't speak up for fear of losing their job or being targeted as a trouble maker"*

VIC Advocates, April 2021 Solutions focused workshop with DRC

"Improved unity between systems is critical to success going forward.

...Clarity of roles, responsibilities & best practice principles at every level, in every system, is required to safeguard people, activate supports and opportunities for individuals & remove the onus on people with disability to navigate and access any system or service”

SA Advocate, April 2021 Solutions focused workshop with DRC

“Circles of Support? Supported decision making mandatory? Effective advocacy training/awareness of human rights in all communities”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“Definitely mandatory funding for people with cognitive disability for SDM [Supported decision making] if they require it.

...I meant that NDIA need to be compelled to provide funding for SDM when the person needs it. At the moment, they state that the decision making gap should be filled by guardianship and advocacy.

...there's now an expectation from NDIA that advocates will make decisions on behalf of people with cognitive disability.

Knowledge about the new [guardianship] act seems to have filtered through somewhat, but there is a very obvious decision making gap, and service providers and NDIA have expectations that advocates fill the gap. We get lots of angry requests from planners and services demanding we attend planning meetings and make decisions.

I think there's often a general attitude that advocates will do substitute decision making without realising the legal framework about it.

...So one of my solutions is around SDM - frameworks, practice guidelines, training. It's also important to define what is a decision and what is an entitlement that doesn't necessarily require a decision.

...I think also supporting disability activism is really important.

...It is also really important to give access to advocacy for people who are unable to consent - advocacy needs to have a defined status so we can advocate for people who can't consent or tell us what the problem is.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“...concerted effort for ongoing positive media stories/social media campaigns nationally? Long term commitment to this?”

...Time and finances required.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“The DRC needs to review independent advocacy systems throughout Australia”

QLD Advocate, April 2021 Solutions focused workshop with DRC

Ensuring access to independent advocacy

“One thing that would make advocacy more powerful is greater recognition of the role of, and right to advocacy as an important safeguarding mechanism.”

QLD Advocate²³⁰

“I think if you look at the experience of the decision support pilot and the number of , and the identification of unauthorised restrictive practices that came with that, it actually again shows that it's evidence of the benefits of having that kind of outreach and tapping into people in that more proactive productive way.”

TAS Advocate, November 2020 Zoom workshop with DRC

“I think advocates should have right of entry, and particularly around people who have no family. The services that I'm thinking of that have whole-of-life, they have so many people there who have no family or no other significant other, and yet they do everything. They go to their planning meeting, they determine who their coordinator of supports is, and usually that's someone who gets along with the provider, and they make decisions for the person as opposed to them being part of making any of those decisions.

So there needs to be some definite safeguards for those people who have nobody alongside them who can help them understand their rights and actually have a real meaningful say in things, in decisions. ...They go along with their service provider to their [agency] planning meeting and they're not going to say in front of them, "Yes, I want..." they don't even know they can change services or what that might mean. So absolutely it shouldn't be, the power shouldn't be ...depressingly this seems like the power is moving back to the providers from what we see...”

TAS Advocate, November 2020 Zoom workshop with DRC

²³⁰ DANA's 2020 Restrictive Practices survey, Response from QLD Advocate

“All people in group homes must have someone to advocate for them who is not employed by the service that provides the staff in their home.”

NSW Advocate, March 2021 Zoom workshop with DRC

“...independent advocacy, people having access to that advocacy, and that advocacy not being prevented through the OPG [Office of the Public Guardian] or EPAs [Enduring Powers of Attorney].”

QLD Advocate, December 2020 Zoom workshop with DRC

“I would like to see more services requesting advocates attend their clients. I would like to see it being "Policy" that an "independent" advocate is called in to represent clients.”

VIC Advocate²³¹

“Ensure the systems are firstly mandated to be inclusive of people with a disability. Include advocates in settings for people with limited/no voice as a part oversight measure. Ensure these advocates are trained in picking up issues, understanding what to do when these issues are picked up.”

VIC Advocate²³²

“NDIS Act needs to explicitly state the right to independent advocacy. State law relating to people with intellectual disability (in Victoria there are many pieces of non-disability legislation that affect PWID), should also be amended to include a right to independent advocacy. This will ensure greater transparency of systems (such as the criminal justice system) which currently do not provide any level of independent advocacy or safeguarding for people with cognitive disability. Obviously inclusion such as this would require an enormous boost in funding at both the state and federal level for advocacy. This should include both state based statutory advocacy services (such as the Office of the Public Advocate in Victoria), but also for not for profit community advocacy services who have an independent voice and a membership based mandate to represent PWID at a systemic level.”

VIC Advocate²³³

“I just wanted to raise one point about the issue of actually advocacy flowing from prison to advocacy organisations in terms of referrals. So I think this is an area that needs to be

²³¹ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

²³² DANA's 2020 *Safeguarding rights and wellbeing* survey - Response from VIC Advocate

²³³ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

improved because we don't find a lot of referrals from the justice system coming to the advocacy, so that advocacy can proactively work with the justice system. So that area needs to be improved, because that's why we don't find a lot of issues that we can be able to work on. So referrals, the link and engaging with the justice system, the advocates, and engaging with the justice system needs to be improved."

WA Advocate, October 2020 Zoom workshop

"there needs to be funded advocates for each person in each group home. There needs to be regular catch ups in a safe place for the client to voice [their] concerns."

VIC Advocate²³⁴

"Anyone who is in supported living accommodation that does not have family members should be allocated an independent advocate."

NSW Advocate, March 2021 Zoom workshop with DRC

"...we've experienced an issue where one of our protégés experienced some issues and because he had a guardian under the Guardianship Act, we had a lot of trouble getting an advocate in for him, and we got literally told that we could not have an advocate for him. Because we have a lot of trouble with citizen advocates - getting them recognised as an official advocate service - that's one thing that we'd like to see changed at some level moving forward with the Quality and Safeguards Commission. It would be really good to get some kind of recognition in there for Citizen Advocacy in some form."

WA Advocate, October 2020 Zoom workshop with DRC

"...we've taken this up with the Public Guardian and their office. We tried to get a protocol of engagement drawn up between their office and all of the advocacy organisations, not particularly naming them, because we were saying that there would be lots of informal advocates who equally should be recognised, because we're obviously speaking or working with the person that they have a, a person has a right to an informal supporter or an advocate. And OPG's response was that they didn't want to sign up to an MOU [Memorandum of Understanding] or a protocol of engagement between guardians and advocates. Instead, they wanted every advocate every time that they ran into a problem to take it up with, escalate it through, the regional manager at the relevant location. They see this as a way of improving their practice. But quite often, when advocates need decisions from guardians, they have to be timely. People are losing out on housing and a whole range of services because guardians

²³⁴ DANA's 2020 Segregated settings survey, Response from VIC Advocate

don't make timely decisions. Obviously they have too many people to see or to even read up on what they're doing. But that's part of a problem, doing things on the papers and then preventing an advocate from doing the work, and we've tried to make the point that advocates can actually make life a whole lot easier for guardians.”

QLD Advocate, December 2020 Zoom workshop with DRC

“An advocate is engaged, in consultation with the person with disability, their family and close connections, who is independent of any association with organisations that provide services to that person with disability.

Independent Advocacy is funded to the level that all people in segregated settings can access an independent advocate.

Opportunities and resources for trust building between advocates and those that require them is provided and funded.”

NSW Advocate, March 2021 Zoom workshop with DRC

“Have more advocates. Make funding available so good people are drawn to and stay in advocacy.”

NSW Advocate²³⁵

“Advocacy so people have the type, level and quality of support they need,

Safeguarding close relationships around the person...”

QLD Advocate, April 2021 Solutions focused workshop with DRC

“...about the standing of advocates with regard to their right to be involved in advocacy work, Citizen Advocacy is primarily focused on cognitive disability as well. We've surveyed our advocates about concerns that they think we should consider in making a submission to the Royal Commission. A couple of areas that have come up for us from that survey are access to information, perhaps also some concerns around health care access and delivery, and I'd say a common thread might be what can be done to prevent and mitigate the problems.

One of the concerns that I have is the application of privacy and confidentiality provisions in the management of disability services. So whether there's something that can be done from a training or an orientation point of view, to sort of clarify what the limits of that are and what

²³⁵ DANA's 2020 Restrictive Practices survey, Response from NSW Advocate

the reasonable expectations are for advocates to have access to information, whether it's about disability service provision or the NDIS planning and management process."

WA Advocate, April 2021 Solutions focused workshop with DRC

"... it's going to take a systemic change through the Royal Commission where, for example, advocacy is given credence and given recognition, rather than just the Act say that, that the actual providers have got systems in place to listen to advocates.

An example of where it's not happening up here ... is one provider has just contacted me again this morning, and the NDIS fragments services so you've got service providers, you've got disability support coordinators, and so on, and different entities. So the actual staff in this residence are telling... one of the residents has got an advocate, a new advocate has come in for another resident - so they've gone to the first resident and said to that advocate, "Can you look after the interests of the other person too because his advocate is not showing up?", trying to co-opt the advocate to help them move these two residents out of that house, and they both don't want to move.

I'm just staggered at turning a whole advocacy process around, so the advocate is working for the provider, not for the NDIS participant, or in our case it's the protégé. But they're NDIS participant, just perverting the process, so they're trying to get an advocate to do their bidding instead of being independent and working in the interests of the person with the disability. They don't think twice about it. I've explained it, that's not going to happen, you can't take on more than one person, it's a one-on-one relationship, and yes, I will ask the advocate who's been called away to work out of town to get up to speed and start dealing with this issue as soon as he can.

And another provider... it's a separate example where the advocate wasn't even given permission to talk to their protégé in the house they were in, and this is not a SIL [Supported Independent Living] house or it wasn't... the house was not owned by the provider, it was the resident's own house, and they announced to the advocate, "No, we haven't got permission to talk to you because of privacy." So crazy stuff... an independent advocate being denied access to a person who's got a right to an advocate.

So dealing with that particular service provider at CEO level and national director level, it's been hard because they are a for-profit organisation, not a not for profit. They don't have any background in disability support and they see NDIS as a bit of a cash cow. They don't want any threat to their relationship with a participant with a very high NDIS plan, a high-value one, and they don't want advocates coming in and rocking the boat.

So to get a cultural change in a big organisation... the first example where they're trying to move residents out without the consent of these advocates, and this other organisation....where it's coming from the top down right down to support worker level, they're saying, "We've been told by the office that we're not to talk to the advocate." When I ring up

that office, they deny it. But it's obviously been the case and they're saying, "Well, we can't allow this because of privacy." I'm saying well, you quote the privacy rules that say consent by a protégé doesn't allow the advocate to talk on their behalf about their welfare?

So it's almost like there is no need, no recognition for the role of independent advocates with some of these providers. And I've talked about this with you, Mary [DANA CEO], that I think we need ...an advocate has official standing, it's not just trying to explain themselves each time and get the goodwill of people at a setting - that there's actually some actual teeth that go with being given the authority or the role of an advocate."

QLD Advocate, April 2021 Solutions focused workshop with DRC

"...it would be good if every service agreement given... whenever people sign their service agreements, that the service provider informs the participant... it should be basically on the service agreement there is a local advocacy service in their area that can support them if they have any issues of abuse, neglect or exploitation, et cetera, so just to make them aware that there's someone out there, an independent person that can help them."

NSW Advocate, April 2021 Solutions focused workshop with DRC

"...I'm not generally into making things mandatory, but in terms of... really concerned about how do we ensure that someone is actually making a decision that they fully understand what they're making a decision about and it is something that they want to do, if they do not have that support? So people with cognitive disabilities particularly, there was a comment earlier about having... when you sign a service agreement, having it spelt out that there is an advocacy service they can contact. Great if they can, but yes, not great if they don't know that they are experiencing abuse, or their rights aren't being met, or if they do not have the cognitive and/or communicative capacity to do that without support.

If I could wave a magic wand, I would see that all people with disability were offered that. Obviously there are people who have no need for that and have the ability to make decisions without any support - but it actually be offered to individuals. Imagine that, hey... folks, imagine that along with that concept of circles of concern, if that was something that was valued in our community..."

VIC Advocate, April 2021 Solutions focused workshop with DRC

Ensuring advocacy sector can meet the needs of people with disability

"We've been working in this area, working personally, for more than 20 years in systemic advocacy. I'm finding quite a lot of issues we put up on submissions in relation to neglect and abuse and discriminations, we find that there is no auditing system, the Government is

funding and the funding is actually being reduced, funding in this sector, when we know it's a very important crucial services that is offered under the systemic advocacy, but we find that auditing system is not followed up, there's no mechanism. Agencies... there's no particular agencies that would be able to support the auditing process and whatever submissions, is just duplicated year to year and this makes it very difficult really to resolve some of the issues. So I will see that... the recommendations will be actually to strengthen the systemic advocacy and to put up an auditing mechanism that will really follow up cases that have been noted, and also legislative agenda to resolve some of the issues. Those would be very strong recommendations we expect probably would be able to resolve that issue... and I really support the idea that individual advocates also, to be mandated reporters so that they can use... those mandatory reporters can be put into the books and those issues can be followed up by the same agency as part of the auditing mechanism. I think that would really help to solve the problems.”

WA Advocate²³⁶

“I notice some people have legal representation within their organisation, which is great, but some small groups don't have it. From our point of view, it's actually being able to access better legal representation and advice, if we're going down those lines. Because sometimes that's very difficult. We are calling on lots of different organisations or people that we know, for some legal advice. Sometimes when you do have a case, and you think there needs to be some sort of legal representation, some small advocacy groups don't have that access on hand. It would be great if we could have something like that. So many hours once a month, that we have legal representation actually can come in.”

QLD Advocate²³⁷

“It would be great to have a free confidential legal call service! Definitely a current systemic advocacy issue & need!”

VIC Advocate²³⁸

“greater funding allocations for advocacy, keep advocacy free, no fee, protection for the legitimacy of advocacy as a right”

QLD Advocate²³⁹

²³⁶ WA Advocate, April 2021 Solutions focused workshop with DRC

²³⁷ QLD Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

²³⁸ VIC Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

²³⁹ DANA's 2020 Segregated settings survey, Response from QLD Advocate

[Regarding Advocacy statistics and reporting to funder] *“...More training is needed in this area. I am grateful I have external and internal supervision to manage such clients.*

Discussions around mandatory reporting and our duty of care as advocates are topic for discussion. Often services will call the advocate and therefore tick their box as they have notified someone of suspected abuse. This is a huge weight for advocates to take on and I am not sure it should be our responsibility.”

VIC Advocate²⁴⁰

“I really do think we need resources in advocacy, because we are seeing so much money poured into transactional systems, into that client provider role. We need money that doesn't go into that... that oversees those and tries to separate all that from a real life person who's not just a creature of support providers.”

QLD Advocate, December 2020 Zoom workshop with DRC

“...advocacy funding, because.... we've had our books closed for the whole of April because we are working completely at overcapacity all the time.”

TAS Advocate, April 2021 Solutions focused workshop with DRC

“...the Royal Commission is obviously aware that the Aged Care Royal Commission recommended an increase in funding, substantial increase, for advocacy for the aged care sector. And I guess all of us are wondering and hoping there will be some recommendations with input from us, with submissions by the Royal Commission about disability advocacy, the system.

The current systemic limitations are really clear - very poor funding across the board, split funding between the feds and the states, and even in Queensland at the moment, discussion about calling tenders for longstanding small disability advocacy programs... funding from next year is only for two years. And there may be tenders called, which means that no one is saying yes or no, but it's a lot of uncertainty in this state when the Royal Commission is still taking submissions on issues to do with including advocacy.

So I would love to see the Royal Commission maybe in a preliminary statement or like they did earlier last year, they released an interim report, start talking about these issues to try to give some direction to the policy makers for advocacy, federal and state. It's in limbo. We're on the edges. T

²⁴⁰ VIC Advocate, "Advocates Zoom In On... Advocacy & Abuse Prevention", December 2020 Zoom discussion

he NDIS has got all the funds and advocacy is really quite marginalised. So it would be good to see some of these systemic issues looked at sooner rather than later.”

QLD Advocate, April 2021 Solutions focused workshop with DRC

Disability support

“More access being given to advocates or “friends” programs to observe what is happening in psychiatric units would help. At the moment, we can only go to the unit on the request of a client and then of course, when the psychiatric client complains, you will often get the response that they’re psychotic so don’t take any notice of what they have to say. There needs to be more independent observation of what is happening inside the units.”

VIC Advocate²⁴¹

“A mandated system of registering any restrictive practice, prior to the practice being put in place, would help. Education about what constitutes restrictive practice is also necessary. Unannounced spot checks would then go some way to helping reduce restrictive practices. Another effective way is to encourage more freely given independent relationships for people who are vulnerable.”

SA Advocate²⁴²

“...we’re so focused in on the disability. Have we ever looked at or outlined what an ordinary life is? Have we had enough conversation around that, because that should be our goal and I’m wondering whether that needs to be addressed a bit because we’ve focused so much on what , particularly with the NDIS and particularly in segregated systems, is restriction. It’s all about what people are not able to do because of a disability and I’m wondering whether there’s not been enough looks at what is an ordinary life...”

SA Advocate, December 2020 Zoom workshop with DRC

“Let people choose their own staff”

VIC Advocate, February 2021 Zoom workshop with DRC

“Legislation/regulation with teeth.”

NSW Advocate, March 2021 Zoom workshop with DRC

²⁴¹ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

²⁴² DANA's 2015 *Quality and Safeguards* survey - Response from SA Advocate.

“Oversight needs to check services that have a majority of business over a population, as they have power to provide or take away support needed by community. Complaints groups need to build trust in disability community, so people want to engage. Sadly too often in the past, people were taught not to complain, or that if they did, nothing was done. This will need a big hands-on approach in order to regain trust of community - Oversight also needs to adopt human rights focus, and really look at services that support people with smaller to no voice, as this is where things are problematic.”

“Staffing business needs to be separate to accommodation profit, this at present is a conflict of interest, to ensure staff are empowered to stand up and do what is right. Group homes need to welcome advocates, they do not do this well.”

“If restrictive practice is ever used, somebody with a university degree in that area of support need, needs to oversee these practices at a business level. Sadly, you leave a restrictive practice in the hands of underqualified, overworked staff and things can go wrong quickly.”

VIC Advocate²⁴³

“Anything that's got a community participation or a community-based day program I find tends to have, the people that we support are far less segregated and happier than in the traditional setting.”

NSW Advocate, March 2021 Zoom workshop with DRC

“I wonder whether a way forward is to have some kind of anti-monopoly style law. So a single service provider can provide no more than just one of accommodation, employment, financial services or planning services to any one individual, whether that's a way of helping to combat some of that potential for abuse...”

NSW Advocate, March 2021 Zoom workshop with DRC

“Day programs where clients do activities in public are best.”

NSW Advocate, March 2021 Zoom workshop with DRC

“Maybe service providers should have a star rating like Job Actives do. This is made public and participants, family or carers can view before selecting a provider”

VIC Advocate, February 2021 Zoom workshop with DRC

²⁴³ DANA's 2020 Safeguarding rights and wellbeing survey, Response from VIC Advocate

"I require, if I'm going to engage with... pick a service provider or help a person pick a service provider, they must be willing to sign a memorandum of understanding with all of the principles for teamwork and partnership and inclusion that I want to see in that service as part of the service agreement.

So I've developed wording in previous... I guess it depends on the actual wording, depends on the particular circumstances of the individual involved, but there is always, and I will always do it now, a memorandum of understanding that the service agrees to work within, and where the family is included, and advocacy is included, and openness and transparency, and all that. And the same if I'm involved in helping a participant pick their service coordinator, all of that again with the service coordinator. I think because this one is working really well for the last eight months, I'm definitely going to push for that sort of thing."

QLD Advocate, April 2021 Solutions focused workshop with DRC

"I also think the quality of the disability workforce is critical, making sure that the workforce is properly trained, is paid appropriately so it attracts and retains quality staff, that all workers have basic things like first aid training, et cetera. I think that's so vital."

QLD Advocate, April 2021 Solutions focused workshop with DRC

"I would just like some more funding to provide advocacy services. We now have a waitlist that has blown out to six months!"

VIC Advocate, April 2021 Solutions focused workshop with DRC

"...we also need properly resourced and empowered inspection bodies such as the Community Visitor Scheme in South Australia."

SA Advocate, April 2021 Solutions focused workshop with DRC

"Maybe we should be nominating these good organisations for awards like the NDS NT [National Disability Services, Northern Territory] Disability Services & Inclusion Awards."

NT Advocate, April 2021 Solutions focused workshop with DRC

"I have solicited feedback from fellow advocates in our organisation and one of the ... suggestions made is in relation to people with disability living in the community in supported environments and to have something that is... to have some other system apart from community visitors... obviously there's issues of privacy, but with the client's agreement or

with the householder's agreement... unannounced visits and potentially. Yes, support around that, because of concerns that this particular worker raised that community visitors, where they have been utilised... it is announced, and it hasn't always been that effective when there have been concerns raised about the levels and the type of supports that people have been receiving..."

VIC Advocate, April 2021 Solutions focused workshop with DRC

"Perhaps as part of the auditing system of providers - recommendations about improvements to problems that are identified in disability service provision could be part of the reporting process?"

SA Advocate, April 2021 Solutions focused workshop with DRC

"...ask people with disability if a service has improved".

SA Advocate, April 2021 Solutions focused workshop with DRC

"I find that some of the new services can often be very inexperienced and ill-informed and dangerous. Perhaps a joint project... where a service has a quality tick by the advocacy national group."

QLD Advocate, April 2021 Solutions focused workshop with DRC

"...about what barriers they face in broadening these positive cultural changes. I think [another advocate] raised an example of [VIC provider] I agree is a good service, a small service... pointed out as is often the case later. That seems like the exception to me, where there's that more consultive, transparent, multidisciplinary approach, because it's an individualised funding scheme and it's about what funding the client has in their plan, so how much time can we devote to them and how many... expertise can we... how much time do we have to spend on the phone, so on and so forth. That's a barrier why it's often an approach of providers to kind of contain a situation, to just address individual as opposed to broadening those practices."

VIC Advocate, April 2021 Solutions focused workshop with DRC

Restrictive practices and behaviour support

"Policies within organisations need to change. Restrictive practices should be kept to an absolute minimum (one or two occurrences per year at most). Effective behavioural

management plans should minimize the frequency of emotional outbursts as well as the need for restrictive practices.”

QLD Advocate²⁴⁴

“...in group homes, with untrained staff, and- people who would know this, I am not aware that there's any signs about basic ...what restrictive practices are. I think it would be a good idea if it was mandatory for there to be signs about a few principles about restrictive practices, especially that they should be used as a last resort, even if they are authorised by restrictive practice panel. Also, to educate workers that small things like not letting residents go out into the community because they misbehaved in the morning, is a restrictive practice. So I think we should work in that direction as well.”

NSW Advocate, March 2021 Zoom workshop with DRC

“So I just wanted to support ... comments around how not just training, but how staff are valued, paid, trained, all of these things to do these jobs. I'm also interested in what funding there is for research in this area, and if that's something that the DRC is looking into in terms of understanding behaviours from the perspective of things like these behaviours being adaptive behaviours, survival. I have had clients who later on have been six months, and they have found out they have actually had infections and that's why they were behaving in certain ways. And the brother has lobbied to get that person seen by a doctor and then that's been the root cause of that. So I am just curious about the funding and research that might be happening or could be proposed around this as well.”

NSW Advocate, March 2021 Zoom workshop with DRC

“If funding bodies attached funding to the reduction of restrictive practice, or the increasing of positive practice, maybe useful”

VIC Advocate, February 2021 Zoom workshop with DRC

“There needs to be mandatory stakeholder meetings held to correlate information for behaviour management strategies to be put in place – ie. seeking a behaviour management plan.”

QLD Advocate²⁴⁵

²⁴⁴ DANA's 2020 *Restrictive Practices* survey, Response from QLD Advocate

²⁴⁵ DANA's 2020 *Segregated settings* survey, Response from QLD Advocate

“...in relation to that, it might be interesting to see what plays out with people reregistering. All providers have to reregister that are registered initially to be a provider for the NDIS, so therefore, as part of that reregistration, there are certainly questions about restrictive practice. And then to reregister, you would have to show that you had an understanding of it and that your staff did. So we might see over the next year or two, an improved understanding across the sector on the ground.”

TAS Advocate, November 2020 Zoom workshop with DRC

“I think even going back to before the review in 2014, first of all, take out the immunity provisions. That makes it all too easy for service providers. Take the short term approvals back to what they were, which is half the duration they are now. And I think the big thing is, which happened to a couple of people just as NDIS was rolling out here-, people who live with restrictive practices should be able to self- manage- and hire their own workers, not have to have them registered as providers as long as they do the same things that they did under Your Life Your Choice, which is the data collection and the reporting, so the number type frequency and the situations around the use of restrictive practices.²⁴⁶

That should be monitored by, well, it used to be the Centre of Excellence, but I can't say that we could rely on the Quality and Safeguards Commission because they're hopeless. I think that there should be a separate independent mechanism that does collect that data and that they do monitor it and that they then say, they step in when they see that either the use is not coming down or it's even escalated, and look at why, whether it's mandatory retraining of staff or even then a forced change of provider.”

QLD Advocate, December 2020 Zoom workshop with DRC

“...the regime in Queensland should apply to people who are under 18, as well as people who are over 18, because it's when people are under 18 that they get set in this pattern of chemical restraint and restrictive practices, that they end up in for the rest of their life. That's one thing that I think really needs to change.

A second thing would be this skills deficit exemption, which is just an absolute, or has in the past been an absolute rort for providers. "Oh, this person doesn't understand how to cross the road, therefore we need to lock everything", but there's never really been any plan in place to say well, how about we teach this person about road safety and then we won't need to lock them in because they will be able to cross the road. So I think there's too many loopholes in the Queensland legislation.

²⁴⁶ See [Your Life Your Choice - Dataset - Data | Queensland Government](#)

...I'm concerned about the fact that in respite, if a person in Queensland was only receiving respite, then you can give them fixed dose chemical restraint with only the permission of their guardian and with no further investigation of whether this restraint was appropriate or not.

So I suppose too many loopholes in Queensland, and too many exemptions, that I would like to see removed. The NDIS partially gets there, but ... they're hopeless in terms of their supervision of restrictive practices, so we can't just rely on them looking after the under 18s because I don't think they've got the resources to do it."

QLD Advocate, December 2020 Zoom workshop with DRC

"There should be a means for the person and their advocate/informal supporter to reject any PBSP [positive behaviour support plan] that they do not feel is adequate."

QLD Advocate, December 2020 Zoom workshop with DRC

"In terms of people, alternatives to restrictive practices, obviously that entails a whole lot of researching - right down from the on the ground stuff in terms of getting, ascertaining people's will and preferences, and being able to support those choices, through to the high level support that people need, in many cases across their lifespan - and that's one of the issues we're not talking about today, that the disability sector is not properly resourced and so many of the things, the concept of last resort, for example, is often first cab and only cab off the rank because nothing else is available. So if government was going to be genuine about this, they would actually make sure that the supports are there, not just decision making supports but the actual support services. And I could give a long story about what we are hearing in New South Wales, when the NSW Government exited the sector, particularly around that sort of clinical support that used to exist within ADHC [Ageing, Disability and Home Care NSW], and there's all sorts of problems that ensued from that. So I would say resourcing... would be a really critical issue to address."

NSW Advocate, March 2021 Zoom workshop with DRC

"Better education about what a restrictive practice is.

Streamline the process of applying for a restrictive practice and make it simpler to understand, for all users. Currently it's unclear when and how to apply for a restrictive practice and to what regulatory body. The current process is confusing for users who are usually making decisions about implementing practices in a time of unexpected crisis.

Make disability services accountable when they breach the restrictive practices laws.

Make regulations about minimum standards of care for services employed to care for people with disability. On the ground, all disability workers should have to have a minimum level of

training so they understand that the same laws apply to the people they work for as themselves. There are widespread (in my estimation) misconceptions about what is and is not a restrictive practice, or perhaps more simply, what is and is not illegal when it comes to working with people with disability.”

NSW Advocate²⁴⁷

“...but I'm just drawing on some of my experience when I worked for a service provider, I was doing facilitation of, like, circles of support, that kind of thing, in terms of positive organisational change. We had this model that got rolled out based on trialling it with one individual who was experiencing what we came to reframe as, like, nonverbal expressions of distress, but a lot of their support workers were reporting them as behaviours of concern and this kind of thing. This person was acting sometimes in what was interpreted as an aggressive manner, they were sort of lashing out with some... yeah, just moving around a lot, I guess in that way, and getting very frustrated. It was causing them a lot of distress and, sort of, not allowing them to go about their day-to-day lives.

And what we devised, talking with that person and their family, was this idea of getting everybody who works with that person together on a semi regular basis, with that person present if they want to be, and their family and, in this case, a behavioural specialist as well to devise like a positive behaviour support plan that was driven entirely by the individual, because another challenge we were having was that everyone who worked with this person wasn't really in regular contact, they were all trying different approaches to assist this person and there was no, like, consistency.

That was really, really successful. We started to put that positive behaviour support plan into play with this person and their anxiety was easing and people were able to, yeah, stay in contact about that, and the person's voice was really central to that process. Then that model was rolled out and trialled with a number of other families too - not necessarily around the same issue, but just it was seen to be really effective getting everyone in communication with one another.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

“...they're making cultural changes and the new CEO... They've been very proactive. They've gone as far as hiring a behaviour support person, like a specialist. They've hired this person for this young man who's 17 because he had... was having behaviours at school and they actually hired this person to assist with the teaching staff and the caring staff there to work with this boy, so stopped... because he was getting a bit anxious and heightened at school and biting himself and stuff, not so much lashing out but throwing things around. So

²⁴⁷ DANA's 2020 Restrictive Practices survey, Response from NSW Advocate

they've actually been proactive and hired a behaviour specialist and they're going to train all the staff and support workers to work with this lad.

I thought that was really positive, a good cultural change for that organisation, and they're being very proactive and it's good business. They see him as a person, not as a burden, or they're treating him with respect, which I think is really good, and talking to the family and involving the family, and all the care workers and teachers, et cetera, to manage him and keep him happy, keep him at school as long as he can. So it's good."

NSW Advocate, April 2021 Solutions focused workshop with DRC

Training

"Advocates need to ensure that training of staff by the family members and people with disability is mandatory and at frequent intervals, with independent scrutiny that it is being done, and for it to be mandatory and public ally reported by all services and businesses and NGOs [non-government organisations] and charities and govt organisations to report what do they use, what the plans are to reduce the use of restrictive practices, how many people were injured by restrictive practices in their care, six monthly, what they are doing to prevent injury and abuse and torture by misuse of restrictive practices, and how they can all be replaced with least restrictive practices at all times. Abolish internal investigations and voluntary policy, and replace with external independent monitoring and mandatory policy tools to protect people."

NSW Carer and family member of a person with disability ²⁴⁸

"There certainly needs to be, when I think about some examples of situations in the mental health sector, you know, a lot of them have a nursing background or, you know, some higher level of understanding. And certainly working with my [family member's] own team, you know, I'm seeing it from another perspective, and it requires constant training, constant, you know, on-call support. So these workers are put in these situations, given very little understanding of the person that they're working with, and they can't necessarily ring somebody and say, "Okay, this is what's happening, what should I do in this moment?"

But yes, I think we definitely need to look at how can we deliver a higher qualification or understanding. Look, it's a tough one because some of the workers that I use haven't got, like, a full tertiary qualification, but they instinctively pick up what's needed and see my son as somebody of value, as a peer. So I'm not sure how you do that in a bureaucratic environment. Bureaucracy is the issue here. It's the big blocker."

VIC Advocate, February 2021 Zoom workshop with DRC

²⁴⁸ DANA's 2015 *Quality and Safeguards* survey - Response from NSW Carer and family member of a person with disability

“...in regards to qualifications and training of support workers, is some of the cultural considerations... here I mean cultural and linguistic background ... Some of the feedback I'm getting from experienced advocates is that that's a two-way process sometimes with recently arrived migrants or workers coming in from different cultural backgrounds, that they benefit as well from some additional training about the environment that they're going to be working in and perhaps more can be done around that area.”

WA Advocate, April 2021 Solutions focused workshop with DRC

“National Standards of Training and Training by proven providers ONLY - not generic RTO's [registered training organisations] just making money. Minimum of Cert IV, must have supervised placement etc etc.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

Recruitment of staff

“...And I would also refocus things in terms of recruitment of appropriate staff. From what I have seen in my professional career, there are some people who should not be working in this field. And you just cannot impart or teach them things about, you know, basic human dignity - Either you understand things like that, or you don't. So there also needs to be an overhaul about relating to recruitment practices of people who come and work with people with disabilities. It really needs someone who has those values and characteristics and are able to do that work with integrity...”

ACT Advocate, October 2020 Zoom workshop with DRC

National Disability Insurance Scheme

“Why is it that some group homes, every single resident in the group home has an identical NDIS plan? How does that happen, when they're all supposed to be individualised to meet the needs of the individual? How can they possibly all have the same NDIS plan?”

It shows you just how much power the landlord, the service provider, has over the residents in group homes. And why doesn't the NDIS realise that that is happening, and do something about it? Why do they approve plans that are identical? Go figure.”

VIC Advocate, February 2021 Zoom workshop with DRC

“First up, I would immediately say NDIS planners and the public guardian not referring people to [boarding houses and hostels] because that's where it all starts, that original referral, the acknowledgment in the NDIS plan that this person is going to live in a level 3 hostel. I'm

finding that quite mind blowing, to what we were fighting a few years ago and getting people out of hostels and boarding houses where that agency was financially dependent on a person's pension, to now that agency is still getting that person's pension and at a minimum around \$80,000 a year in NDIS funding and still not providing anything else to a person, people are still sharing bedrooms in hostels. ...So I guess the referral, that initial assessment and the assumption that this is a service, that it's even seen as a service provision at all needs to be stopped."

QLD Advocate, December 2020 Zoom workshop with DRC

"...Support Coordinator should be accountable to their clients over and above the service that employs them."

NSW Advocate, March 2021 Zoom workshop with DRC

"I just think there's a lot of pressure on service providers financially in trying to adjust their shifts and having to justify themselves to the NDIS to get paid. It does impact on our clients, especially the training seems to be on the cost for the service provider. You've got the issue of where, at last minute, services get cancelled and then the service provider is not sure if they're going to get repaid. They may have already committed for staff. So I know I'm on the other side here, but this model of the service provider having to care for our clients and then billing the NDIS, in a lot of cases they get squeezed in the middle and sometimes they lose money and cause themselves and their employers a lot of business stress, if they're doing the right thing. And sometimes in order to survive, our clients have got to miss out because they're not getting paid for stuff. So I just think that's the other argument, that this model of trying to guess when you're going to provide the services and when you're going to get paid, it makes it hard for a lot of service providers, and a consequence of that could be that a lot of them are going to go to the wall, the smaller ones, and other services with our clients, are going to miss out. So just making that comment."

NSW Advocate, March 2021 Zoom workshop with DRC

"I just had something, going back to the lack of service providers and the lack of choice. We've been doing a bit of outreach and I've been on Kangaroo Island fairly recently, and there isn't much choice there with the service providers. And what I'm seeing a lot of is people going to their GP and the GP suggesting perhaps they should look into NDIS, and they have quite serious disabilities that they've just been managing on their own, on their farms, and things like that, and also people having strokes and injuries later in life and then trying to access NDIS."

But there's nothing there that assists them to help, so we're coming in and trying to do as much as we can, but there's also really low literacy because there's few jobs, so people leave school early. So they can't really just be given forms to fill out. We've got to go... it's a big-time commitment to read through with them, to make sure that they know what they're going into, and even if they do get NDIS, they have such a slim choice of providers. And if they don't... a lot of people know everyone, if they don't want to go with that provider, they choose not to engage and then they're just not getting any services or support.

So perhaps something linked in with the GPs, advocates, social workers, that they could be directly referred to as a third party that can help them with those processes, and encourage them to stay engaged, because I'm finding people are becoming engaged and then can't contact them again. It's too hard."

SA Advocate, April 2021 Solutions focused workshop with DRC

Advocates and NDIS

"...one way that I can see would improve things, is to allow people to have an advocate, someone outside the system to come into NDIS meetings and things like that to make sure they're taking an overview of the whole plan, and that everything is fairly simple for a person with disability that may not be able to speak up for themselves. But we're seeing as an organisation that a lot of the time our advocates aren't allowed to have access to the NDIS plans. Therefore, they cannot get that overview, even to the point of going to an NDIS meeting and everybody else having a copy of the NDIS plan, and the advocate didn't have a copy of that.

So what we'd like to see as an organisation is, I don't know, a law, a policy put in place where somebody who doesn't have involved family, and has an advocate there for that reason, that advocate would be able to view those things for them to be able to effectively advocate for them and have that overview. If they're only allowed to see selected documents or have selected information, they can't get an overview of the whole life and identify that there's abuse going on.

So it does say in the NDIS plans, and things like that, that people are entitled to have an advocate if they want to, but we don't always see that followed through. So that's the solution that I can see that would...something that needs to be pushed more and checked and made sure that everybody... anybody with disability is shown that that is an option for them."

WA Advocate, October 2020 Zoom workshop with DRC

"We know that some work has been done for people ...who live in segregated settings, who don't have informal support to have access to an advocate through the NDIS process, and mandating something similar to that over here, I think in the short term would at least, make sure that people are aware of their rights. Yes... they have access to an advocate, their voice

is being heard, but long term we need to make sure that people who are at risk, you know, that we are funding circles of support, so we're funding supported decision making, that we are building into the supports they're getting, these safeguards that they need to protect them in the long term and build up that safety around them. And it's something that I know the NDIS is talking about, but if and when it becomes a reality, we don't know."

WA Advocate, October 2020 Zoom workshop with DRC

"Make sure advocacy is promoted as a highly valued service within NDIS."

VIC Advocate²⁴⁹

"It seems to make sense that everybody who has the public guardian also has funding allocated for advocacy in that regard, if not being assigned a particular advocate.

But part of the difficulty is, we see the difficulty with family members or people, just the NDIS has a lot of difficulty in people being [appointed nominee]. There's so many issues around that process, that if they can't get that right, then how on earth would they get advocacy right?"

NSW Advocate, March 2021 Zoom workshop with DRC

Parenting supports and NDIA

"The attitude of the NDIA is a significant barrier, and it is this attitude that leads to parents relinquishing custody [of] children with a disability.

At present, NDIA Planners accuse families of seeking "baby sitting" for their children if they seek additional in-home supports. Parents are treated as negligent and lazy, and I know of one case where the NDIA contacted Child Safety and attempted to report parents for neglect because they were trying to commence transitioning their 17 year old son into independent living.

This is insulting and upsetting for families and needs to stop. The NDIA must recognise that the parents of children with a disability are often required to provide significantly more support to their children than parents of children who do not have a disability. This is embedded in r3.4 of the National Disability Insurance Scheme (Supports for Participants) Rules 2013, but is routinely ignored by the NDIA. Instead of criticising parents, the NDIA should instead allow:

- *More willingness to providing respite for families.*
- *More willingness to providing "core supports" (support workers) for children with more complex physical and intellectual disabilities (including children with challenging behaviours caused by disabilities such as ASD [Autism Spectrum Disorder].)*

²⁴⁹ DANA's 2015 *Quality and Safeguards* survey - Response from VIC Advocate

- *There also needs to be better access to support/training/counselling services for parents/siblings of children with a disability to help them better support the child. NDIA is against funding being provided for people other than the participant; however, it is of significant benefit to the participant if their family is better trained to understand the disability.*

The changes to Carer support arrangement made by the Commonwealth Government have removed significant supports from families (including significant access to respite) and replaced them with online self help assistance. Respite is now only available in very limited "emergency" situations. Self help services in no way replace the direct access to respite that was available through Carers Queensland.

The NDIS must recognise that it can no longer rely on other government agencies to provide the respite services that many families desperately need.”

“Better co-ordination between the NDIA and Child Safety: NDIA planners should attend stakeholder meetings for children with a disability who are state ward, particularly where the lack of NDIS funded in-home supports is part of the reason for relinquishment. Without proper in home supports, the child will not be able to return home and is being deprived of their parents. Similarly, if the issue is behavioural, the NDIA plan must include significant funding for Capacity Building to reunite the family in a way that is safe for everyone”

QLD Advocate²⁵⁰

“In some situations, having an NDIS plan has made some difference for parents, but only in the context of being able to be prepared and ready and get to access on time, which has been really difficult for some parents, as [QLD Advocate 1] said. And the child is out of the region, and there tends to be more travel that has to happen for the parents. I think the NDIS plan has helped make that work a little better, but it is very hard to get them to think outside of the way that they have always done things. We have tried for decades to get them to think about shared care arrangements, anything that is a bit outside the box. They don't want a bar of it. They don't know how to make it work. Again, you have to be the person that gives them the idea. They don't come up with anything on their own and they just do what they have always done, which is reduce access. And parents lose... feel really done to in that process, and parents can end up losing all contact altogether. I think there is great potential for NDIS participants. The NDIS seem to be listening, that supporting a parent in their parenting is... a reasonable thing to do.”

SA Advocate²⁵¹

²⁵⁰ DANA's 2020 *Child Protection Systems* survey, Response from QLD Advocate

²⁵¹ SA Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

Justice supports

“If we as advocates can see that people with disability do need, or benefit from, a liaison service in the court system or legal system, using an insurance model mentality, they would be reasonable and necessary supports, which would be very cumbersome and difficult to program into somebody’s individual support plan. But it would make sense from an insurance model, to have an NDIS funded disability liaison office at courts, so that it would be a streamlining of reasonable and necessary supports given at point of need.”

NSW Advocate²⁵²

Services Australia

“You could have your own hearing on welfare alone. Some of the issues I have with my clients at Centrelink can be with some of the more aggressive clients. If the person on the other end of the phone doesn’t know they have a disability, they can feel like they are getting abused, and they can’t get any further: this person is not listening to me and there are barriers there. So maybe if there was a way to identify the disability earlier in the conversation or some way of flagging that, so the person on the other side of the phone can be a bit more considerate, or if there was another whole process or a channel that provided easier access.”

NSW Advocate²⁵³

“Raising the DSP [Disability Support Pension] so people with disability are perhaps in a position to be content creators and more involved in mainstream productions, and so on, might go some way to addressing some of those upstream kinds of approaches or cultural attitudinal changes I should say.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

Justice

“The legal profession... the lawyers, need to gain some skills in how to communicate. The one good thing I see, out of the assessment and referral court, is a consistent lawyer that is there right from start to end, and they spend time with communicating. We are trying this a little bit in places like VCAT [Victorian Civil and Administrative Tribunal], in terms of some community legal services are trying it, having a liaison person at VCAT for example, and that’s not criminal justice. But why can’t we have a disability liaison that is independent of the court workers and court system based at courts? They are very busy places and, when I’m sitting in the public gallery with a client, I can see a multitude of people with disability who are

²⁵² NSW Advocate, "Advocates Zoom In On... *Criminalisation*", October 2020 Zoom discussion

²⁵³ NSW Advocate, "Advocates Zoom In On... *Barriers to Employment*" October 2020 Zoom discussion

not getting support, wouldn't know how to ask for support, and probably wouldn't know what an advocate is.

The legal profession understanding indicators that someone may have a disability would be a starting point - upskilling them, having a liaison person. We have family violence liaison now at courts, why can't we extend this to disability liaison? Some people may be for or against it, there could be issues, but it needs to be explored further. I have seen from Villamanta Disability Rights Legal Service had for a while a trial period at VCAT and members at hearings were saying 'we think this person needs some support to understand what is happening' and they were referring them to the liaison person that was there. It was once a week for a trial period.

I have thought of having disability liaison at hospitals as well. These are all institutions within our society that do not have supports."

VIC Advocate²⁵⁴

[Several TAS Advocacy organisations] "were involved in making some videos to try to make the pathway before you go to the Magistrate's Court and then, when you're at the Magistrate's Court, more of a level playing field if that's possible for people with disability. And I know that that really came out of the disability justice plan in Tasmania that was updated only a couple of years ago and I know that the justice area is keen to improve, and the lawyers that we've been working with are keen to make changes, and to hear about what's wrong with the court system, and is there anything that they can do, you know, quite easily to make changes, and if there are more systemic concerns, what are they and that they'll start talking about them, and doing some work across the justice area. So that's been fairly positive I think. Because they came to us, you know, rather than us having to go to them to say this is an issue, they already know it's an issue for people with disability. So I think that's been positive."

TAS Advocate, November 2020 Zoom workshop with DRC

"...there is a need for introduction of a redress scheme for the DRC, accompanied by waiver of time limitations for people who have experienced abuse – suggest adopting model of institutional sex abuse redress scheme, with addition of funded advice for people exploring common law claim so it is not purely no win, no fee model".

SA Advocate, April 2021 Solutions focused workshop with DRC

Police Stations

"On the topic of advocacy, the initial/first barrier that needs to be overcome when someone goes to a police station to make a report or is a victim of crime, is for someone to be assigned

²⁵⁴ VIC Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

an advocate, they need to be recognised as in need of an advocate. A lot of people with intellectual disability will not identify readily that they have an intellectual disability, which means the police just think this is another so and so person and treat them accordingly. This is one of the primary issues that has to be dealt with - How we do that other than an attitudinal change from police not jumping to the worse conclusions to start with, I don't really have too much insight there.

Advocacy is a great benefit to anyone interacting with the justice system in terms of making sure they are treated right, their voice is heard, and helping them understand the process. One thing we have noticed, especially in terms of dealing with criminal justice issues is, it is important for the advocate to have a relationship with the person they are advocating for, especially on topics where they have been the victim or they think they might get in trouble, as they may or may not be comfortable with a person who rocks up out of nowhere and says I'm your advocate. In cases where a person doesn't have a pre-existing advocate, there should be some sort of mechanism to allow the advocate and person to develop at least the beginnings of a relationship so that they can understand the person and better help guide them through the process, whichever path that might take."

SA Advocate²⁵⁵

"The other thing I would quickly add around legal changes is to strengthen the availability of the NDIS to people in custodial settings - as this would hopefully set them up with supports on release, and thus render them less vulnerable to neglect and abuse whilst also improving their social health determinants."

ACT Advocate, October 2020 Zoom workshop with DRC

Child Protection Systems

"I have a client... it has been five years in the making, but the family now has full reunification and they both have mild intellectual disability, and they also lived in a rural area. There were supervised visits for a significant period of time. It was very short spaces. In one of the meetings, we discussed it. We said one of the parents has an NDIS package and one of the goals was for parenting, around parenting, to be supported in the NDIS package and to be a parent.

We worked on those dynamics, and at one stage Child Safety would not help ...it took a lot of work to get them to think outside the box using NDIS support workers and support services, to do some work with the support services on what they were hoping for them to do. So that they can start doing supervised visits for child safety, and because they were rural and coming out every 4-6 weeks, it was not a significant amount of time. This would start happening every week, and then twice a week, and then we went to semi-supervised and it

²⁵⁵ SA Advocate, "Advocates Zoom In On... Criminalisation", October 2020 Zoom discussion

was agreed that support services would report any concerns to child safety and at the same time it was using their NDIS package. So that is the way that they managed to get through, and to get through from supervised once a month to supervised twice a week and into semi-supervised and then unsupervised to then full days, sleepovers, and now that child is in full unification - that took five years.

The parents were a significant part of the child's life through that whole time. And I was very lucky because I became involved while the mother was pregnant.

They did, at one stage, want to put the child in foster care in another region which would have meant that they would not have ever seen the child. I took that one to court and we did win that.

It was a long process but it can work. You have to make sure it's part of the parent's goal and then you have to really try to negotiate with child safety. It did work, but we had to give them the ideas. We had to get them to start thinking outside the box of how they could do this, supervised visits and unsupervised, through using the person's package."

QLD Advocate²⁵⁶

"There should be a lot more work that gets done through the pregnancy. I think that that's where things fall down. They wait for the crisis situation, when the child is removed and then all the parenting and everything goes in. It should be the other way round. There should be more considering of prevention, rather than waiting for that to happen.

I... actually have [a family member] from child protection who works in that role. It's always interesting for me to hear the other side of what they are going through on their end. Of course they see a huge amount of gaps, and I'm in there with my advocacy hat on, especially when it comes to children with disability and some of these parents.

And of late, it's been about communication with NDIS. Child protection workers should have training with NDIS, and understand that system, because that is not marrying up. That's one of the issues. If they were all connected and communicating, and the training was there for the child protection workers, maybe some of that stuff would be coming natural to them to communicate, instead, they just don't have the training. I've been training [my family member] in some of the NDIS stuff so that they do understand it when they come up against the child with a plan, or the parent has a plan, and how to make that better for them.

That should be across the board. Not us doing that randomly in our lounge room. That is one thing that they need training in."

VIC Advocate²⁵⁷

²⁵⁶ QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

²⁵⁷ VIC Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

“What is the support that people need and how are they going to be able to take things up? We always try to think about it in the context of first-time parents, and as things that you don't know. And the way you find that out is not that you have child protection come in, it might be grandparents or your mother or sister in law and people don't have that, so they need something that approximates that and often that is only paid support. It is also about how child protection here have done that with a parent as part of their investigation assessment stuff - they could step in with a parent who could take the child home and there was a plan and during that period they can assess what the parent needs etc. Then they just pulled the pin on it because they said they could not keep funding at that level, and it was significant support, but that did not mean it would be ongoing. That was about two things - it was about assessing what was going on, but also helping that parent to build some skills at the same time. There was no investment. Even though they did it, they did not have goodwill around it. They were not clear so that when they make the plans, or even if it is safety plans or things like that, that they are really bad at giving information in detail, so that the parent understands what is required of them. They will give these overarching statements and you have to make sure your child is safe and at home, but what does that mean? We need to have specifics around that. Safety might mean that ‘You always have to keep your front door locked’ but if you don't say that... people will not necessarily think of that themselves, because they might think about safety in a different way. For child protection services to be more clear and ... [not] saying, “You are a great mum, you are doing a great job,” but at the same time the axe is coming down and they are taking children away. The way that they engage with people must be different. Don't pretend you are doing something, and do not be brutal in the way that you are doing it.”

SA Advocate²⁵⁸

“You talk about needing the funding to support these families, but they have to look at the fact that, say a child is into foster care when they are first born until 18, that is \$250,000 that the foster carer gets until the child is 18. Why can't they be proactive and use some of that money early on to help that family get that child back with the family rather than foster carers until they are 18. That would be proactive and more appropriate for them to have the extra support, as opposed to all this money going into it. Imagine how many kids are in care until they are 18, and that is the minimum that the foster carer gets, on top of Centrelink and the other stuff, and it would be better utilised to bring the family back together instead of separating them.”

QLD Advocate²⁵⁹

²⁵⁸ SA Advocate, Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

²⁵⁹ QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

“It does make is very difficult from that perspective, but they do need to focus more on the family unit. When they do these long term orders, there should be rules about when... ‘Yep, you’re taking on that child until they’re 18, you’re the grandmother or another family member, the foster carer, whatever, and you have to facilitate these things and if you do not do it, you are no longer the carer.’ It should be, ‘You have to facilitate the relationship with the family.’ As soon as the orders are coming in, families are ceasing contact with the parents and the kids will never get to see the parents, and the families are getting away with it and that is not OK. And it should be enforced, and if you are taking on the responsibility, you should be assisting in facilitating that. If you cannot facilitate it yourself, go through a contact centre or whatever it might be, but that child still deserves to have that relationship, and should do it in a nice way rather than cutting off contact entirely, because that is not helping these kids when they get older - They do not know who they are or where they belong in the world because they’re not family anymore.”

QLD Advocate²⁶⁰

“...child safety officers (CSOs) need to be trained in disabilities. When we talk specific disabilities, we often have to explain what that means for the person because they do not have a clue. Get them trained in disability and specialise. It does not have to be everyone but any person that has a disability, their CSOs need to be trained in disability to understand [and to be] getting the advocates involved. Because the clients that get referred after the fact, and come with these documents they have signed, and then we explain to them what that means, and they do not want that, and you tell them that they signed it and that is what it is because they have signed it. They thought it was something completely different, and so that is not fair for those families, and it is breaking them up unnecessarily.”

QLD Advocate²⁶¹

“Every single parent or child that goes through the Department that has a disability, it should be, not just offered, but the referral should be done to an advocacy organisation. And until you can check the capacity of the person, someone has to be there, and just like a recognised entity, it should be along the same lines – ‘this person has a disability, they should have a person in the room’, whether it is an advocacy member or a family member and there should be an advocate in every single meeting.”

QLD Advocate²⁶²

“That grief and loss, that counselling should happen immediately, for both the child who has just lost their whole family, especially when they've gone into care with a stranger and not

²⁶⁰ QLD Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

²⁶¹ QLD Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

²⁶² QLD Advocate, "Advocates Zoom In On... *Child Protection Systems*", November 2020 Zoom discussion

family, so they need to have that counselling to support them straight away. As for the parents, it would be like having a miscarriage. Having that child growing and then losing it at birth, that grief is real. It is not just something that is pretend and goes away. They need that support to acknowledge that this has happened, and work through that stuff. Without that, that trauma will always be there. If that's not acknowledged, that's where you end up with children in prison, because they end up in those other systems. They end up on these lists. 'Such and such has had a baby, so we need to keep an eye on her' Another red flag. They get put on a list because they've been in care."

QLD Advocate²⁶³

Education

- *"A human rights focus.*
- *Education Department could request all students have an Individual Learning Plan, therefore it would create common practice instead of disability specific practice for students.*
- *Parents need to understand their rights in regards to school environments for their children.*
- *Schools need quick access to professional specialists supports to educate, guide, support human rights focus for teachers and educational staff."*

"All students have Individual Learning Plans, all students are supported in the way they need as individuals to learn and to obtain support to learn, so that all students are supported to access and be included in education, regardless of individual diverse needs."

VIC Advocate²⁶⁴

"The violence, abuse, neglect and exploitation of people with disability is normalised, accepted as part of culture. Need to get into the high school, Higher education like TAFE, local groups etc, to start early to change the transgenerational trauma."

WA Advocate²⁶⁵

- *"Inclusive education in accordance with the definition of General Comment No.4 of Article 24 - The Right to an Inclusive Education , of the UNCRPD [United Nations Convention on the Rights of Persons with Disabilities].*
- *Become an inclusive culture, where people with disability are seen and heard in daily life. National strategy required. Australian Coalition of Inclusive Education (ACIE) have*

²⁶³ QLD Advocate, "Advocates Zoom In On... Child Protection Systems", November 2020 Zoom discussion

²⁶⁴ DANA's 2020 Access to Education survey, Response from VIC Advocate

²⁶⁵ DANA's 2020 Advocacy and Abuse Prevention survey, Response from WA Advocate

created a 10 year roadmap with 6 key pillars to help realise inclusive education called Driving Change: A roadmap for achieving inclusive education in Australia.²⁶⁶

- *Easily accessible reporting structures.*
- *Greater access to independent free advocacy.”*

NSW Advocate²⁶⁷

“Obviously mandatory reporting of abuse [or] neglect of children is good practice. To access education, all schools must be held accountable. This begins with the education department, they need to be an inclusive organisation who will not tolerate a student with disability not getting an education.”

VIC Advocate²⁶⁸

“...from 16 years of observation, it's an educational process. It should start with school kids. We should be talking to school children about human rights. Aboriginal kids out in those schools should have that information. It's not going to happen overnight...”

NT Advocate, November 2020 Zoom workshop with DRC

“In relation to the education, I think there should be an independent complaints board outside of the department, because what happens is when people make a complaint, it stays within that system and then it just feeds backwards and comes back to the beginning. I have found that then that child is set up where they watch everything that they do, and then they get suspended, and it keeps going that way. So I really believe an independent complaints board should be made available for people with disability and their families to actually have it addressed properly, and I have seen where it should not be up to the family and up to that person to do that, but where they've actually moved schools or found a school that has a more supportive environment and completely different person.”

NSW Advocate, March 2021 Zoom workshop with DRC

“...just wanted to also mention in this example, the issue was really with a family member wanting her daughter with an intellectual disability - she was in a support unit at a regular primary school, a local government primary school - and she wanted her daughter to be in the mainstream classroom and so through building the capacity of the family member, she had lots of meetings with the school, and the principal, and the teacher, and they ended up transitioning her daughter across successfully to the point that now the principal has decided

²⁶⁶ [Driving change: A roadmap for achieving inclusive education in Australia – Australian Coalition for Inclusive Education \(acie.org.au\)](https://acie.org.au)

²⁶⁷ DANA's 2020 Segregated settings survey, Response from NSW Advocate

²⁶⁸ DANA's 2020 Safeguarding rights and wellbeing survey, Response from VIC Advocate

that the whole school would be changed,- and he's started an initiative called Collaborative Classrooms so that all the children that are in those support units are now moving into the regular classroom as often as they can. And it's obviously a work in progress, but it's been a school-wide change as a result of that one individual case.

And, yes, obviously that whole point is that we would like the Commission to be mindful about the importance of inclusive education at the very start of a child's life, to be included and to end the othering which seems to be a high-risk factor that is involved with any forms of abuse, neglect and exploitation. And we'd really like the Commission to be looking at sort of that long-term data on the impacts of life course, so when you are in a segregated setting versus being in a mainstream setting, if you are a child with a disability what are those impacts when it comes to leaving school, getting a job, getting tertiary education, and things like that. That is something that's really lacking at the moment in this country.”

NSW Advocate, April 2021 Solutions focused workshop with DRC

“Students with disability truly present and participating in ordinary schools and classrooms means that the future support persons/practitioners will have direct experience that can inform their work. Schools are a microcosm of society and that is where we need to start with meaningful inclusion”.

SA Advocate, April 2021 Solutions focused workshop with DRC

Health

“Education of medical professionals - they do not recognise their responsibility to ensure there is informed consent... Anytime there is increase in medication there needs to be accountability for that.”

VIC Advocate, February 2021 Zoom workshop with DRC

“I want to mention that Medicare dental rebate scheme act is discriminatory towards children with [disability] under 18 as they are not allowed to use this rebate if they have any dental work done in hospital, it has to be done at the dentists rooms to claim the rebate. But when these kids with disabilities can't sit in a dentist's chair they have to be anaesthetized, so don't have the [same] option as mainstream kids.”

NSW Advocate, April 2021 Solutions focused workshop with DRC

See suggestion above in [National Disability Insurance Scheme](#) subsection in relation to better linkages between General Practitioners and NDIS access, especially in rural and remote areas.

Housing

- *“Address the disability housing crisis*
- *Let people choose their housemates”*

VIC Advocate, February 2021 Zoom workshop with DRC

“One of the primary things that our organisation feels very concerned about is the lack of affordable housing and that what happens to people is they're forced into congregated settings. I know that there's all sorts of ideas about what constitutes a group home. We would say that a house with, there can be group homes of one. However, what happens to people is that they are constrained by services. There are a whole bunch of SILs - Supported Independent Living - organisations that get a whole lot of money which looks like the old block funding model. Even though it comes from a participant's plan, it's actually not in the participant's plan, it's a quote that is done by the SIL provider. Very commonly, they don't involve the person or the family in that process. They then get allocated a whole bunch of money which is used to fund rosters. It does not fund individual support for people or meet their individual needs, and it has to stop. And what we need to be thinking about is a home of your own.

Now, there will be people that definitely want to be living in a house on their own, but there'll be other people who want to be sharing, and we need to think differently about sharing, and I know that there are programs in place in some states, like “homeshare”. We don't have something similar to that in South Australia, but a place where you can be looking for somebody to share with you, that doesn't have to be a person with disability. It might be a friend, a neighbour, a family member.

We have ILO [individualised Living Options], which is a part of the NDIS. We need more and more and more of ILO being... people being engaged with ILO, so that they can start to think about what home looks like for them...

...ILO, I think, is the thing that's going to give people more flexibility. I think that what happens - and this, no matter what the service provider, the SIL provider, might say that they want to do, the practicalities are that they cannot do that because they've got three or five people living in that house, and the response to... so there's no way to respond to an individual need. So if I wake up in the morning and I go, "Oh, my God, there's a really good concert on" or "there's a really good band playing at the local pub and so I want to go up there," and the other people that I live with, they're not interested in rock music, or whatever it is, and I want to go, there is no capacity within those SIL arrangements for a support worker to be able to be rostered or provided to support that person. It takes weeks. So if you want to make an arrangement to go to a concert, you've got to let your support service know with at least two weeks [in advance], and quite often that doesn't happen because what they have to then do,

because you might have a small amount of money in that SIL quote which is for social and community participation, and so they then have to go to their pool of workers and work out who it is that's available to do that.

So the person has no choice and control. I get really over that term, but this is about when a person has a plan. They need to be able to have choice and control within their plan. We know that they don't have it more broadly, but within a plan it should be there.

So I think that the money needs to be in the person's plan, not paid to... I'm not real clear about how those things are paid - but I understand that SIL providers get their SIL money paid, I think, it's probably on a monthly basis, and it's on the basis of what they've been allocated. It's got nothing to do with how that support is provided to the person.

If it sat in the plan, even if you lived in a cluster environment... I think it's harder when you're living in a congregated environment, but if you're in a clustered environment, you would be able then to say to your service provider, who might be providing services to all of those people in there, you've got the money and you've got the power and so you can have... you might have a schedule for your week which you're then able to say to whoever that service provider is, "I need support on these days and now I want to buy some extra support", but you get the power and control over that, not the service provider who is constantly telling people, "Oh, I'm sorry, we don't have anybody to take you to swimming today" or, "How about you go to the movies next fortnight?", or, "Okay, every fortnight on a Wednesday we'll look at what your next fortnight is going to look like so that we can organise our roster around that." That is not access to the good things in life.

I get to decide when I want to go to the movies, when I want to go to the pool, when I want to drink wine... you know, all those sorts of things, and people who are living in those environments do not get those choices. No matter what people say, they do not get those choices."

SA Advocate²⁶⁹

"Investment in affordable housing will better serve people with disability and others who are congregated, homeless, poor etc.

...a real home of your own is a primary protection from violence abuse neglect and exploitation....it is a place in which you can choose who enters, it is a place you can retreat to if needed, with relevant and appropriate support, you can exercise your human rights in the context of citizenship and ordinary life."

SA Advocate, April 2021 Solutions focused workshop with DRC

²⁶⁹ SA Advocate, April 2021 Solutions focused workshop with DRC

Meeting the needs of First Nations people with disability

"I think mainstream disability advocacy services that most of us are from, I think need to look at potentially their structure and their make up. It's only very new for [NSW Advocacy Organisation], but we are certainly having allocated, identified positions. ... We know there are a lot of small advocacy services, so perhaps it's about thinking about paid advisory roles as well as employee and team member roles. "

NSW Advocate²⁷⁰

"...more appropriate LONG TERM funding for identified positions to support"

VIC Advocate ²⁷¹

"...If we can use existing networks as well. There's a lot of organisations - like medical services, land councils - organisations that are already set up. Instead of reinventing the wheel, let's use them. They are doing work in their local aboriginal communities. Make contact with them and build networks up, because there is a lot of work being done out there, and lots of us sitting around the table here now may not know about it. They could educate us a bit as well. Maintain that contact with the existing networks that are already in place in different towns."

NSW Advocate²⁷²

"...Some families have high levels of English literacy and have had a lot of engagement with services over a long period of time, and are pretty comfortable with using complaints processes. We've got other families who might have huge issues.

One family I'm thinking of, there's five adult children who all have brain injury from petrol sniffing. The mother of those adult children has a psychiatric disability, the father of those adult children was an alcoholic who has since passed away, and that family just don't have the capacity despite lots of support. And often they're really focused on the here and now, today, have we got enough food, have we got shelter, is there some domestic violence going on in some aspects of that family? They're not interested in a process that's going to be protracted. They want a fairly immediate response, and a lot of complaints processes are quite protracted. So that's another disincentive to people to actually follow through with those processes.

²⁷⁰ NSW Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

²⁷¹ VIC Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

²⁷² NSW Advocate, "Advocates Zoom In On... Advocacy for First Nations People", November 2020 Zoom discussion

But some families just don't have the capacity. They're in survival mode and they let a whole lot of really inappropriate things happen, and they don't care because it's more important to worry about whether you've got food that day...."

"From our perspective... that family that I just talked to you about, what's made a difference is one of the people in that family has met the threshold for an NDIS plan, and it looks like now she will end up in Supported Independent Living (SIL). Her plan is being reviewed. That has made a huge difference to her life. She is getting yeah, we're kind of at the opposite end of the threshold. We're saying to people that services can actually help you and support you and you can have better life outcomes. So she's gone into a SIL situation which is extremely flexible and culturally appropriate, so not like normal SIL. She's really, really, well supported, and she is getting the care that she needs and that care, the kind of upshot of that, will be that she will be able to better look after her own children and make sure they go to school. And hopefully they will have, kind of, better life outcomes than her because she ended up at 16 having a stroke from petrol sniffing. She's had three children, one of them cared for by another family member, two others are still in her care, and the SIL is going to make the difference to her being able to provide adequate parenting.

I guess from [our organisation's] perspective... often people have the solutions themselves. Those solutions involve being able to stay in community. You shouldn't have to go away to get the support that you need. You shouldn't be told if you need services you've got to be in an urban centre. But listening to the innate wisdom that people have about what they need to resolve their situation, and doing everything you can to act on that, yeah, trusting that individuals actually do have the capacity to identify what they need to have a good life."

"... there has been a few stuff ups, there's no doubt about it, but all along the way they've maintained a commitment to trying to provide a culturally appropriate service, and for this particular lady and for others of ours who have come from remote, coming from remote into a SIL environment is a huge shock because people are used to just doing whatever they want to when they're out in community. So to have a SIL that is much more open, and flexible about supporting people in the way they want to be supported, is a real benefit."

NT Advocate, November 2020 Zoom workshop with DRC

"Poverty provides the ideal environment for abuse, neglect & exploitation of people with disability in remote Indigenous communities. The poverty is largely caused by dependence on Centrelink income, support payments which are inadequate particularly in situations where there is a cultural obligation for people with access to resources to share with their extended family. Often times, people with disability are left without money for basic needs such as food, clothing & bedding. This is a complex and many layered matter, but part of the solution is increasing Centrelink payments to support people to have a better standard of living."

NT Advocate, April 2021 Solutions focused workshop with DRC

“Primary prevention in the form of community education is essential to begin the process of changing attitudes about violence and abuse. In remote communities, we think the education should start with school children and then continue at all levels of the community. People in these communities are not necessarily aware of their human rights, they are struggling on a daily basis to have their basic needs met. It is important to ensure that people understand their rights and have support to have their rights championed. Advocacy is a critical aspect of educating and supporting people to access their rights.”

NT Advocate, April 2021 Solutions focused workshop with DRC

“In remote Indigenous communities there is an important role for ‘Champions’ in primary prevention. Senior, respected people, with good knowledge and understanding about Human Rights and Disability Rights, who take every opportunity to educate and support people in the community about these matters.

...Story telling and using video resources to tell the story about rights can be very powerful in Indigenous communities.”

NT Advocate, April 2021 Solutions focused workshop with DRC

Meeting the needs of refugees and asylum seekers with disability

[QLD Advocacy organisation] “has made a recommendation already in our submission to the Royal Commission that both the Australian and state and territory governments should agree in principle that refugees and asylum seekers with disabilities currently on temporary protection visas or no visas, should be given access to specialised disability supports while residing in Australia or its territories. This would include, of course, the National Disability Insurance Scheme and we understand that that would require the Act to be changed.”

QLD Advocate²⁷³

Meeting the needs of culturally and linguistically diverse people with disability

“Ensure trained culturally and linguistically diverse people are employed in advocacy, promoting disability advocacy within the communities from a human rights perspective,”

VIC Advocate²⁷⁴

²⁷³ QLD Advocate, April 2021 Solutions focused workshop with DRC

²⁷⁴ DANA's 2020 survey, Advocacy for people from culturally and linguistically diverse communities - Response from VIC Advocate

“... in [our area], it's a very multicultural area and we come across people with disabilities and their families that are not connected to services, don't even understand, never heard of advocacy. We've met somebody recently who's 45 years old, intellectual disability, not on the NDIS, being cared for by his 95-year-old mother, from a CALD background, who is no longer able to look after this person.

So I think the Government needs to, and even advocacy organisations maybe, have a little bit more funding to go to have more of an impact on people from cultural and linguistic backgrounds in a point of view from providing information, basic information, as to what services are out there and how to access advocacy organisations.”

VIC Advocate, April 2021 Solutions focused workshop with DRC

Meeting the needs of women and girls with disability

“A system that supports women to exit violent, abusive situations with their children, that also provides home supports to ensure practical things, like cleaning, cooking healthy, and mental health are supported for the family unit. Supportive education around understanding rights and healthy relationship skills should also be priority. And ensuring, if engaged with CP [Child Protection] system, there are adequate supports to understand the system and what is required.”

VIC Advocate²⁷⁵

Case study demonstrating how advocacy can protect healthcare rights:

“A female resident had been using Depo-Provera²⁷⁶ in excess of 20 years. Prolonged use however can cause gingival bleeding of the gums and a decrease in bone density.

[There was] concern about the prolonged implications that this will have, and the Depo Provera was ceased.

The mother of the resident felt that her daughter did not like to experience menstruating and was unable to cope. There had only been minimal spasmodic spotting which started 9 months after the Depo-Provera had been stopped, so her body was readjusting.

Staff indicated that they had been supporting the resident in changing her sanitary aids and this had been working well.

²⁷⁵ DANA's 2020 survey, *Child Protection Systems* survey- Response from VIC Advocate

²⁷⁶ DEPO-PROVERA is an injectable form of contraception. Each injection protects you from pregnancy for 3 months. It works by inhibiting the hormones that are needed for the release of eggs from your ovaries.

The mother, along with the residents key worker, then went to a gynaecologist and organised an Endometrial ablation, which is used to manage heavy bleeding, which the resident was not experiencing and can cause sterility.

As an advocate, I was concerned about informed consent;

Informed Consent, in a health care setting, is the procedure whereby patients (clients) consent to, or refuse, an intervention based on information provided by a health care professional regarding the nature and potential risks (consequence and likelihood) of the proposed intervention. The Victorian Charter of Human Rights requires that consent for medical treatment be free, full and informed:

A person must not feel they have to give informed consent simply because the clinician believes it is necessary for their treatment or in their best interests or to please a family member or carer. It needs to be determined whether there is no less restrictive way for the patient to be treated.

Advocate followed this up with the Gynaecologist, how he has provided this information. The Gynaecologist hadn't done this, and had relied instead on the mothers wishes.

As there had been:

- no option to have a second gynaecologist's opinion as to whether the resident required this invasive surgery; and*
- no opportunity to monitor the menstrual cycle for 6 months to observe if the resident was experiencing any adversity and there is a need for surgery.*

With advocacy intervention, surgery was postponed until further monitoring was done.

The mother was rather aggrieved by this outcome. Lengthy discussions were had regarding the matter, eventually resulting in an affirmed approach moving forward.

Staff kept menstruation charts for the resident, following up on this matter has indicated that the resident has ceased menstruating due to moving into a menopausal stage of her life."²⁷⁷

Meeting the needs of children and young people with disability

"Advocacy programs could be enhanced by more flexibility in age groups for advocacy -ie: emancipated young people with disability who are not living with families or engaged with Children's Services."²⁷⁸

²⁷⁷ DANA's 'Submit an Advocacy Case Study' form received this anonymous input from an advocate in October 2020.

²⁷⁸ DANA's 2020 *Advocacy and Abuse Prevention* survey, Response from QLD Advocate

Appendix B: Barriers to making complaints

DANA ran an online survey in April 2015 during the consultation on the NDIS Quality and Safeguards Framework.

Survey respondents were asked to “**Select which category you identify with most strongly**” from the following list:

- Disability advocate
- Person with disability
- Carer of a person with disability
- Family member of a person with disability
- Disability support worker
- Disability service provider

1. **What barriers are most commonly encountered by people with disability when trying to make disability service complaints? (Please include any relevant stories or examples)**

[Open-ended response]

2. **What factors influence a person's decision not to:**

- **make a complaint;**
- **pursue the formal recognition and/or resolution of that complaint;**
- **seek a remedy, and compensation, for the grievance; or**
- **report unethical or unsafe practices or criminal behaviour?**

[Open-ended response]

Some respondents left the second question blank.

Carer of a person with disability from New South Wales:

Barriers to complaints:

Not wanting to cause problem for anybody and getting somebody whom really cares about what is happening to you eg. It took several visits to different hospitals until somebody in care to give my son [John] the treatment that he needs. That shouldn't happen to any child and the NSW Police in my opinion should do a course in learning about Mental disability

Factors in not making complaints:

Because Mental Disability is a, real hard for the carer or the person whom is taking care of the person. It is all about availability of time and money, compensation of loss of wages, physical abuse and stress. At end of the day the list can go [on].

Person with disability from New South Wales:

Barriers to complaints:

They take your complaint and then ignore it.

Factors in not making complaints:

- being too unwell
- Illiteracy
- beauracracy
- being told your complaint is a systemic level and there isn't a way to deal with systemic issues.

Disability advocate from Victoria:

Barriers to complaints:

not being given information about their rights and the support to understand them, dealing with the bureaucracy and chain of command in organisations, complaints procedures not being accessible, and people not having the support to understand the processes. Service providers protecting their own backs and their "brand".

Factors in not making complaints:

Fear of retribution, e.g. loss of service, personal intimidation, being called a trouble maker. Feeling that you are on your own without support. The length of time it can take to process as the complaint works through the different levels of the process e.g. Individual staff, CEO, Board, external complaints bodies. Fear of the legal processes, e.g. involvement with the police, courts tribunals statutory bodies etc, state legislation.

Disability advocate from Victoria:

Barriers to complaints:

1) Their concerns are dismissed, belittled, not taken seriously. For example, a client who lives in a group home has complained many times about the lack of same-sex support workers available for personal care. The group home denies they have any obligation to meet her request.

2) Fear of retribution including fear of physical assaults, seclusion, neglect, abuse and loss of services. The parents of a young man with autism called our service to get support to

complain because they had been told that they would lose access to day services if they continued to complain.

3) The person is unable to access means for making their complaint (e.g. do not use verbal communication, do not have access to a computer), or have no reliable representative (e.g. family or support worker), or they do not know that their treatment constitutes abuse. A 16-year-old school student was being isolated in a classroom at her school at lunchtime but her family was unaware that the school had an obligation to support her social inclusion at the school.

Factors in not making complaints:

- 1) Fear of retribution
- 2) Scared of losing their services
- 3) Are bullied into not complaining by the service provider or family member

Disability advocate from Queensland:

Barriers to complaints:

Fear of retribution whether real or perceived is often an issue. Another is fearing support workers jobs may be in jeopardy. The person who often receives the complaint is the coordinator of the supports. ie many people are unaware that they can complain to external bodies eg CRRS [Complaints Resolution and Referral Service], Community Visitor, Disability Advocate, Funding Body ie Disability Services or Mental Health.

Factors in not making complaints:

Feeling of inevitability that nothing will change may deter people from lodging a complaint. Level of literacy, not wanting to rock the boat, worry that complaining may result in an escalation of the poor treatment ie to be punished.

Disability advocate from Victoria:

Barriers to complaints:

Barriers can be inclusive of service apathy, services forming unjust or inappropriate negative opinions about people with a disability who may stand up for their rights. People in the service system who are not open to thinking about solutions to issues arising, or being limited in the capacity to amend or change a service system.

Factors in not making complaints:

Fear of any repercussions, including access to the service, behaviour that is unsupportive or non inclusive. Individuals' confidence, understanding and supports to navigate systems of

complaint or grievance. The maturity and robustness of individuals in organisations to hear and take positive action around complaints.

Disability support worker from Western Australia:

Barriers to complaints:

Most DSO [Disability Support Organisation]'s deal with this well but when the person is supported by the state-run disability supports it is impossible to complain

Factors in not making complaints:

PWD [people with disability] are scared of retribution if they complain.

Disability advocate from Queensland:

Barriers to complaints:

* accessibility * unaware of their rights

Factors in not making complaints:

* too much time and effort * feelings that nothing will change and everything will stay the same

Disability service provider from Northern Territory:

Barriers to complaints:

Making a complaint itself, learning how to make the complaint, and the establishment believing that the complaint is real and relevant. Insufficient communication between person and organisation. Lack of advocacy to assist the person. Staff's point-of-view more influential than the person making complaint.

Factors in not making complaints:

Too difficult to make the complaint, no support to put forward a complaint, the complaint not being believed or taken seriously. Seen as a 'trouble-maker'. Upsetting the status-quo.

Person with disability from New South Wales:

Barriers to complaints:

People not having the confidence to make a complaint and, if they make a complaint, may feel they are doing something wrong and are not willing to make a complaint because they feel unhappy.

Factors in not making complaints:

United Nations Convention on the Rights of Persons With Disabilities. People not letting people with disabilities know about the Disability Service Standards and their rights.

Disability advocate from New South Wales:

Barriers to complaints:

Access to appropriate support if no informal support network in place to assist with complaint process. Many clients are still dependent upon their service provider for information. Lack of supporting evidence in service support file notes. Eg. a client with a diagnosis of legally blind having advocacy info available that is in small print that they can not read.

Factors in not making complaints:

Family members/carers. Lack of time/energy. Disillusioned with system / internal service provision process & higher levels at NSW Ombudsman. People with disability unaware of the complaint system & available support. Lack of acknowledgement of their concern / fear of reprisal re: loss of service.

Disability advocate from Queensland:

Barriers to complaints:

That they will lose a service or be mistreated further. Don't know how to articulate their concern.

Factors in not making complaints:

Are so used to being treated unfairly they don't know any different. It all takes too long. Puts you in the hot seat. Feel like they are the bad person. Confusing with all the different faces.

Disability advocate from Western Australia:

Barriers to complaints:

communication barriers. Lack of confidence, or being told they will lose the service if they complain! Lack of access to a computer or internet or being non-verbal.

Factors in not making complaints:

Fear of losing service, fear of reprisal, lack of choice.

Carer of a person with disability from New South Wales:

Barriers to complaints:

Who would listen? Before [NSW Advocacy organisation] began to help, I had spent hours on the phone trying to get somebody, anybody, to listen to the problem of poor health

management, lack of communication (unless it was for me to help them do their job). It seems I need a translator to work out what all the symbols mean. It would be a great help if someone could speak in ordinary English.

Factors in not making complaints:

Sometime it's just too hard, to keep trying to get the information on who, or where to get the best results. I tried to get somebody to listen to my concerns about my foster son being over medicated and conflicting stories about his finances, because I live five hour drive from Sydney, I have to depend on phone contact, I could not find a directory that could help me get to the right people who would or could help.

Disability advocate from Western Australia:

Barriers to complaints:

Disregard for value of the person.

Factors in not making complaints:

Care givers being denied services.

Family member of a person with disability from Western Australia:

Barriers to complaints:

Often people with disabilities lack a voice and confidence.

Factors in not making complaints:

Fear of reprisal. Intimidation. Unsure of themselves.

Disability advocate from Western Australia:

Barriers to complaints:

Lack of awareness of their rights and of the National Standards for Disability Services. No one to "stand beside" them and support them through the process as the person is not aware of independent advocacy services. Internal complaint mechanisms inadequate.

Factors in not making complaints:

Fear of reprisal - such as withdrawal of a service.

Disability advocate from Western Australia:

Barriers to complaints:

Being perceived as "a nuisance" and fears of retribution by the service provider or an individual support worker. Internal complaint mechanisms of some organisations inadequate. The organisation does not keep to promises of "confidentiality" when a person makes a complaint.

Factors in not making complaints:

Person not aware of their rights. Fears of withdrawal of service (even where the service is perceived as inadequate). The person may not be aware that they can obtain support through the complaints process through independent advocacy. The perception of HaDSCO [Health and Disability Services Complaints Office, Western Australia] as a "toothless tiger".

Disability service provider from Northern Territory:

Barriers to complaints:

Personal opinions not considered. Decision-making made predominantly by others. Tokenism of own input not tolerable. Ganging up of Service Operators against person/s and families with disability.

Factors in not making complaints:

It's all too hard - put in the hard basket. Need physical assistance to put in and make a complaint. Poor computer / internet skills. Inability to express one's thoughts into sentences that can be understood. Inability to organise appropriate persons to assist the process to completion. Negativity of service providers, carers, family members, to believe the complaint.

Disability advocate from South Australia:

Barriers to complaints:

We respond to situations of complexity and significant vulnerability, where individuals may not know about or be able to access complaints processes. The complaints or concerns raised by vulnerable individuals are very often dismissed by their disability service. Vulnerable persons are blamed for the problem regardless of the action or inaction of the service.

Factors in not making complaints:

that damage has already been done and making a complaint may lead to further wounding through backlash/retaliation by the service or service worker. Outcomes are typically very poor. Person feels further wounded by processes that get dragged out.

Person with disability from New South Wales:

Barriers to complaints:

The time it takes to make the complaint and the turnaround time for getting the issue addressed. Inaccurate information about the complaints process being provided to the person with disability, and unfortunately sometimes the people with disability is their own worst enemy for various reasons. Including inappropriate behaviour and abuse of care from workers. Unrealistic expectations of the outcomes due to the demands being placed on service providers, or miss use of the allocated care support hours, et cetera.

Factors in not making complaints:

There are various influences on a person's decision not to make a complaint, pursue recognition and/or resolution, seek a remedy, and compensation or report unethical or unsafe practices or criminal behaviour which include: a previous bad experience of outcome (possibly due to not using an advocate), the time, effort and resources needed to make and pursue a complaint to the end (which may have financial implications, particularly if a complaint is unable to be conciliated through the AHRC [Australian Human Rights Commission] and the decision to either drop the complaint or pursue it in the courts), feeling vulnerable if the complaint is unsuccessful, and there is little choice of support services able to provide the services needed (particularly in rural and regional towns), and left with receiving the support from the same people that the complaint was made against.

Disability advocate from Victoria:

Barriers to complaints:

Lack of knowledge about where to go or how to go about putting in a complaint. I find that most people with disability who are unhappy just suffer in silence. I had a situation recently where the mother of a young lady who had been admitted to our local psychiatric unit had asked the staff where they could get an advocate and were told that they would have to go to Melbourne. We actually have a memorandum of understanding with that particular service. I put in a complaint and received a telephone call and apology from the manager of the service and an undertaking that their staff would be better informed but it meant that the client spent a lot more time without advocacy support than was necessary. It was just fortunate that the mother happened to be talking to someone who informed her about our existence.

Factors in not making complaints:

Fear of losing what they have. Being in a regional community, we have limited choice in what service providers are available. Feeling powerless. Parents of young people with disability are possibly the worst for not wanting to rock the boat. Of course, this then passes on to the young person.

Disability advocate from Victoria:

Barriers to complaints:

Complaints procedures are commonly cumbersome and difficult to negotiate. And it's not that easy to find out what the complaints procedure is in the first place. People are not taken seriously unless they have an advocate beside them through the process, and can be easily fobbed off.

Factors in not making complaints:

"It's too hard. There might be retribution. I could lose the service all together. I will hurt people's feelings. The police won't believe me. Mum or Dad will be upset with me. In a small community, everyone will hate me for rocking the boat". If you seek compensation people accuse you being "all about the money", when really there is a principle at stake. They need support to tell their story, which is often quite a painful one. One of our clients was sexually abused as a child in an institution, and wants to tell her story to the Royal Commission. She asked a support worker to help her begin this process. The support worker immediately informed the client's sister about the past abuse, without the client's permission. This was an enormous breach of trust, which has possibly derailed the whole process.

Disability advocate from Queensland:

Barriers to complaints:

Complaint forms and mechanisms not user-friendly. Lack of knowledge about when and how to make complaint or support necessary to make a complaint. Fear and inequality of position of person with disability relative to service provider.

Factors in not making complaints:

Inequality of positions, fear of retribution and/or withdrawal of services.

Disability advocate from Australian Capital Territory:

Barriers to complaints:

They are not taken seriously. They do not have the capacity to force service providers to comply.

Factors in not making complaints:

They are not listened to or taken seriously, many a time they have tried but it is not until an advocate makes a call on their behalf that the service providers kicks into looking at a resolution.

Disability advocate from South Australia:

Barriers to complaints:

Being heard effectively. Not being taken seriously, believed or understood. Stereotypes and reputations which mean that opinions are formed and "solutions" determined on false assumptions at times. Complaints bureaucracy that expects people to be able to read, write and talk with a stranger in a huge office somewhere about some very personal issues. Fear of retribution from those against whom the complaint is being made. Organisations that "close rank" around offending staff or wanting to "sweep things under the mat". Lack of consistency and familiarity with the staff receiving complaints (constantly retelling the story to yet another stranger). Confusion between wants and needs. Confusion as to who can do what. Lack of support through journey of making a complaint.

Factors in not making complaints:

All the barriers from the previous question and being talked out of things by others. Too many cooks can add to confusion regarding these decisions for people who have little experience of good decision making.

Disability advocate from Victoria:

Barriers to complaints:

Barriers are that they don't have someone to support them. They need to get in touch with an advocate first. Their voices are often not listened to, even though they should be. They also get frustrated when they make an official complaint, and even then, things don't improve. Mediation is not the answer. Complaints body with power to require improvements from service provider is essential.

Factors in not making complaints:

In the past they have not been successful in getting the improvements they sought. They are worn out by the constant need to complain. They know that they will get one thing sorted, and immediately will be confronted by another issue that needs sorting. They are afraid of repercussions - they have complained in the past, and have been 'punished' for doing so. Often, they can complain and even if the complaint is satisfactorily followed up, and improvements are made, it is not clear that they can also seek compensation.

Disability advocate from New South Wales:

Barriers to complaints:

For intellectual disabilities: Unable to understand what is required. Non-verbal Fear of reprisals. No knowing who to talk to to get action.

Factors in not making complaints:

For intellectual disabilities: Fear of reprisal. Not being able to express what they want. Not knowing who to report matters to. Not knowing about the complaint avenue. Not

understanding that they have rights. Feeling totally controlled by those who are supposed to be taking care of them

Disability advocate from New South Wales:

Barriers to complaints:

Service providers who have a 'knows best' mentality, where it is difficult to discuss their opinions. Making a complaint, regardless of disability, can be an anxious and awkward for people. Fear of retribution is a significant factor!

Factors in not making complaints:

Loyalty to their support person, the issue may not necessarily be with the support worker, but with the organisation of whom they work. Potential previous experience where a complaint has not been dealt with in an appropriate manner.

Disability advocate from Victoria:

Barriers to complaints:

Communication methods and the response when they do so.

Factors in not making complaints:

The time it takes and, as I said, the ramification on their necessary services.

Disability advocate from Victoria:

Barriers to complaints:

Knowing who to talk to in the origination to raise there complaint, particularly if they wish to complain about their key worker. Clients find it difficult to gain access to senior management in an origination, where an advocate can.

Disability advocate from Western Australia:

Barriers to complaints:

Whomever that person with a disability makes a complaint to, does not take their complaint seriously and disregards this. Response time for a complaint.

Factors in not making complaints:

Overly complicated or drawn out complaints process, which often discourages people with disabilities from going through complete complaints process and they will often 'give up' rather than progressing. Inappropriate information is provided from disability service providers. e.g.

providing a client a copy of the NDIS guidelines and expecting that client to understand those guidelines and interpret them accurately.

Disability support worker from Western Australia:

Barriers to complaints:

Organisations trying to keep the complaint in-house and informal. Family members discouraging the person from 'making a fuss'. Inability of person to cope with the stress of a lengthy complaint process.

Factors in not making complaints:

Lack of awareness of rights and advocacy. A culture of unsafe or abusive practices being the norm. Fear of repercussions.

Family member of a person with disability from Queensland:

Barriers to complaints:

Most people with disability feel or are threatened by the potential loss of support, physical abuse or abandonment. Disbelieved, not given credence to their grievances, being told the service is 'compliant with standards', being told they will be evicted if they complain about support (landlord and support both supplied by same service provider). Department staff telling the person that they will process the complaint against a service provider or their own staff, but will not divulge what actions are being taken or what the outcomes will be.

Factors in not making complaints:

Most people with disability feel or are threatened by the potential loss of support, physical abuse or abandonment (these barriers prevent them from proceeding). Lack of support to make the complaint - not enough advocacy services or supports to do so. Not having their complaint being treated with the respect or belief in their complaint, so they give up.

Disability service provider from New South Wales:

Barriers to complaints:

Sometimes the complaint is made to frontline workers that may listen, but not carry the complaint any further.

Factors in not making complaints:

Lack of knowledge of processes and rights, especially in regards to pursuing resolution.

Disability advocate from New South Wales:

Barriers to complaints:

Complicity of government departments and advocacy agencies who are also service providers.

Factors in not making complaints:

They have a disability which does not allow them to interact with the system. Often unethical or unsafe practices or criminal behaviour is the norm in their life and they "don't know what they don't know".

Person with disability from Western Australia:

Barriers to complaints:

Feeling of inadequacy. Feeling the service or provider is a professional so must be right. Not coping with confrontation. Being patronised by head workers. Feeling like going into a lions' den where workers have support, mentors and back up.

Factors in not making complaints:

Intimidation. Lions' den - superior status. Confrontation. Reporting. Workers play incidents down, blame other clients for the incident, not their own mistakes or inadequacies. Fear of being the scapegoat.

Disability service provider from Victoria:

Barriers to complaints:

Lack of empowerment

Person with disability from Victoria:

Barriers to complaints:

My biggest barrier to making complaints is the enormous amount of time and energy it takes. My disability means I don't have very much energy and only a short window each day where I can do things that require complex thinking, like make complaints. To be able to successfully complain I must be able to explain the situation to somebody, discuss what outcomes I want, then let that person do all the hard yards involved. Advocates are the ONLY group who do that.

Person with disability from New South Wales:

Barriers to complaints:

1. Not knowing who to complain to.

2. Being shut down. I used to be an OCV [Official Community Visitor] in NSW and I, like any other OCV who did their job, was pressured by OPG [Office of the Public Guardian], ADHC [Ageing, Disability and Home Care, New South Wales], others, to not progress serious abuse matters. When the Deputy Ombudsman, Robert Fitzgerald, started commanding non compliant OCVs to come in for a fireside chat, that was, to coerce them to stop raising complaints, I left.

3. Not having their complaints taken seriously. Think how the NSW Ombudsman deals with reports of abuse against people with disability, that is, to always minimise the seriousness of those complaints and to bizarrely characterise them as service delivery improvement issues. Scary but true.

Factors in not making complaints:

Complaints mechanisms are set up to frustrate complainants. Moreover, even after pursuing them, NSW outcomes are typically crap. This is especially the case where the complaints are about acts of violence against people with disability. Who takes people with disability seriously? Not the police. Not the Ombudsman. Not Victims Services.

Disability support worker from New South Wales:

Barriers to complaints:

Communication barriers. Power imbalance. Lack of knowledge about how to make the complaint.

Factors in not making complaints:

Often people are unaware of their rights in the first instance. When they are aware, they often don't complain because they fear retribution or loss of support.

Family member of a person with disability from New South Wales:

Barriers to complaints:

Being non verbal. Not knowing how to access complaint services. Not knowing the language to lodge a complaint.

Factors in not making complaints:

Fear of retribution.

Disability service provider from Victoria:

Barriers to complaints:

Finding the right person to speak to. Understanding the process.

Factors in not making complaints:

"Its all too hard" or "Won't make any difference".

Disability advocate from Northern Territory:

Barriers to complaints:

Fear of retribution. Lack of confidence. Unclear about whether it is a real complaint. Not sure exactly who to complain to.

Factors in not making complaints:

See above: Fear of retribution, lack of confidence, unclear about whether it is a real complaint, not sure exactly who to complain to.

Family member of a person with disability from Queensland:

Barriers to complaints:

Understanding their rights and the system, navigating the system, being confident enough to make a complaint, fear of authority figures, accepting their lot and having the communication skills to articulate themselves clearly. Being able to manage all aspects required from personal to systematic. Example story: An NDIS planning process with an inexperienced planner, results in a person receiving less than they are entitled to, which becomes apparent to their service provider. In the old world, the service provider would advocate for them and rectify the problem. In the NDIS world, who does that and who pays for it?

Factors in not making complaints:

Lack of confidence and understanding to successfully navigate and negotiate the systems and services.

Disability advocate from Tasmania:

Barriers to complaints:

Service providers not taking their complaint seriously. Lack of confidence to speak up. Lack of adequate communication skills. Fearful of speaking up due to potential reprisals (eg cuts to service). Lack of an adequate and effective external complaints handling system.

Factors in not making complaints:

Lack of knowledge of and access to independent advocates. Promotion of advocacy still has to rely in many cases on service providers providing people with information about independent advocacy. The most vulnerable people in the service system have no means of contacting advocates. There needs to be a national Community Visitors Scheme established - Tasmania has no scheme at present.

Disability advocate from New South Wales:

Barriers to complaints:

Feeling they will not be listened to or taken seriously. Some feel they will be victimised if they complain.

Factors in not making complaints:

The feeling of not being taken seriously, personal exposure, not being listened to, and being victimised against. Without support, these issues seem too hard or unreachable to most.

Disability advocate from South Australia:

Barriers to complaints:

Defensive behaviour at all levels of Human Service provision. Systemic policies and practices that prevent individual assessment.

Factors in not making complaints:

Lack of confidence, knowledge and skill. Fear of reprisal or retribution. Lack of confidence that they will be heard or that any change will occur.

Disability advocate from New South Wales:

Barriers to complaints:

1. Fear of retribution;
2. PWD [people with disability] may be too intimidated by service provider;
2. Complaints are not taken seriously;
3. Lack of ability to follow complaints process;
4. Referrals to ADHC [Ageing, Disability and Home Care, New South Wales] or Ombudsman, which may be too intimidating or burdensome for the PWD.

Factors in not making complaints:

The above barriers.

Disability advocate from Victoria:

Barriers to complaints:

Fear. Lack of knowledge of rights.

Factors in not making complaints:

Assuming they have no right to make a complaint, or that it will be 'too hard' to make a complaint, or that there will be repercussions (negative outcomes) from the service provider if they complain, or that they will look stupid, or not be believed or taken seriously.

Person with disability from Queensland:

Barriers to complaints:

Literacy. Being heard.

Factors in not making complaints:

Fear of reprisal. Fear of being ignored.

Family member of a person with disability from South Australia:

Barriers to complaints:

Some with a disability are reliant on a relative/carer to make the complaint on their behalf, without a person who is willing to do this a complaint, may not be placed on behalf of the person with the disability. Language and understanding/comprehension when making a complaint may also be an issue. Lack of awareness with regards to disability rights and laws.

Factors in not making complaints:

Possible repercussions from the organisation/person complaint made against, eg. poorer service for the person who has the disability. Exhaustion and fatigue from seeking formal recognition/resolution, as organisations sometimes do not take responsibility for their actions. Lack of funds to support going to court, and fear of not being believed.

Person with disability from South Australia:

Barriers to complaints:

Fear that services will be removed or lost, fears that the support worker or service will be displeased. Lack of a formal complaint system. Lack of confidence and assertiveness.

Factors in not making complaints:

Whether support is available. Perceived potential to be successful in complaining. Feeling as if one needs to be thankful rather than making complaints. The complexity of the process which may exclude some people.

Disability service provider from Australian Capital Territory:

Barriers to complaints:

Someone else would like to speak on their behalf, rather than support them to communicate their own positions.

Factors in not making complaints:

Not understanding that they do have a choice, have a voice and have the right to be heard.

Family member of a person with disability from New South Wales:

Barriers to complaints:

Told no money, not enough staff to handle complaint, this isn't within our operational model.

Factors in not making complaints:

Feel they will then be seen as 'difficult' to deal with and make life harder for the client.

Family member of a person with disability from Queensland:

Barriers to complaints:

Lack of confidence. No awareness of their right to complain. Lack of access to an independent advocate. Disability has reduced their capacity to make complaints verbally or in writing. Eg. A women aged 51 with a mild intellectual disability was prevented by her mother from taking a walk outside her ... shared accommodation. Her mother lived 5 hours drive away, but the staff did not allow the daughter to leave the house unless she was accompanied. There was no attempt to allow dignity of risk for this activity and no risk management treatment plan was prepared.

Factors in not making complaints:

Lack of confidence and fear of repercussions. Ignorance of complaints process. Need for an independent advocate

Disability advocate from New South Wales:

Barriers to complaints:

Nothing happens when they make the complaint to the service provider, no one takes action. Fear of retribution from staff and the service. People withdraw complaints suddenly following threats, is it worth it? Lack of knowledge about what they can do about the complaint.

Factors in not making complaints:

threats, concern over their placement - removal of service. most people don't seem to want to have compensation, they just want an apology and get on with their lives.

Disability advocate from Australian Capital Territory:

Barriers to complaints:

I find that people with disabilities do make complaints but they go no where. For example, a young man in after school care complained to the service because he felt bullied by the manager, he approached our service after waiting for a reply to his complaint for 8 months. On the other hand there are people that are too afraid of retribution, and do not want to complain because they fear services will be withdrawn. I always have to prepare with clients and let them know what I am going to say to the service provider and agree that I will not rock the boat.

Factors in not making complaints:

One of the things that I often hear is that they do not want this to happen to someone else. Some would like to obtain an apology, the acknowledgement that something wrong was done to them, and that the person is sorry. Other times the person is seeking compensation as they believe that the behaviour is illegal and the service should be punished. The only way to punish someone is to hurt in their pocket.

Disability advocate from Queensland:

Barriers to complaints:

A cafe owner witnessed a support worker being extremely rude to a person with disability whilst assisting with lunch. The cafe owner contacted the manager of that agency and informed advocacy that she did not know if she was more distressed by what she witnessed or by the manner in which the manager spoke to her. The whole complaint was recorded and given to the department who then eventually deemed that there was no basis for a complaint.

Factors in not making complaints:

Are aware that other's have complained to no fruition. Feel threatened that supports will be withdrawn if one makes a complaint. Usually the end result is to change service provider.

Disability advocate from Queensland:

Barriers to complaints:

People with disability are very dependent on the service where they need to make the complaint. They do not want to cause any upsets, and know that there is always retribution in some form. Often when a complaint is made, there is no outcome and the situation remains the same or becomes worse. People are often not believed or have no credibility. People with disability can often find it hard to articulate what has happened, and need support to form a complaint and to follow through.

Factors in not making complaints:

People can be worried about being exited from the service. Have difficulty in finding appropriate legal advice. People do not always receive a positive response from the Criminal Justice system when they report an incident.

Disability advocate from New South Wales:

Barriers to complaints:

Fear of retribution by the service provider for complaining. They feel more confident to complain through an advocate with support. This empowers them to stand up for their rights.

Factors in not making complaints:

When the pwd [person with disability] has been informed that it is ok to make a complaint, and when they are aware of their rights and what is wrong and right, self advocacy can empower pwd to speak up and report serious offenses.

Disability advocate from Queensland:

Barriers to complaints:

The complaints are vetted by the very people they are directed at.

Factors in not making complaints:

Previous experiences. The parents of profoundly disabled people are TIRED, never forget that. They are tired from constantly looking after their children. They are tired of making complaints to organisations that DO NOT CARE.

Disability advocate from New South Wales:

Barriers to complaints:

Ease of access to the complaint process. Lack of education around complaint process. Service providers do not take clients complaints seriously.

Factors in not making complaints:

Service providers talking clients out of making complaints. Complaints processes may seem too much of a problem and client could fear repercussions. Lack of support within services to support clients to make complaints.

Disability advocate from Queensland:

Barriers to complaints:

People are unable to contact the right person within an organisation to raise the complaint. People don't like to talk, or are unable to express themselves, over the telephone eg: reluctant

to contact CRRS [Complaints Resolution and Referral Service]. People are unable to put their complaint in writing and without immediate access to an independent advocate - remain silent.

Factors in not making complaints:

Often they are told "don't worry about it, it doesn't matter" or "I don't believe you, our support workers say your not telling the truth" or "I don't want to complain because they (the service provider) will cut my hours and I need help every day" or "I don't want to complain because I have to live hear and it will make it worse".

Disability advocate from New South Wales:

Barriers to complaints:

Funding. Service providers lack of creativity with drawing up service plans for the individuals needs. Lack of trained staff. Service constraints. Abuse and neglect.

Factors in not making complaints:

Unaware of the service's complaints procedure, frightened that it might impact on service support. Not worked in the past. Services not prepared to listen. Unfavourable previous experience in doing so.

Disability advocate from New South Wales:

Barriers to complaints:

Lack of understanding of their rights. Inability to navigate the complaints process. Staff unwilling to assist in making a complaint.

Factors in not making complaints:

By far the majority of both clients and carers state fear of retribution by staff. The greatest fear is that person the complaint has been made against will continue to work with the client and cause them discomfort and awkwardness. The process is too hard and nothing comes of it. Other clients think the person is a trouble maker and can retaliate.

Disability advocate from New South Wales:

Barriers to complaints:

1. Isolation. People with disability feel isolated physically and/or socially.
2. Communication. Most people with disability require assistance in articulating their needs and in communicating socially.

3. Awareness of service and support in the community. People with disability are often constrained in terms of knowing and accessing the services and support.

Factors in not making complaints:

1. Not aware of their rights and avenues of complaint.
2. Lack of effective support, someone to represent their needs and wants.
3. Barriers in making complaints. Making complaints and following through to the end is a tedious process. The current complaints system in Australia requires certain knowledge and skills such as writing, communicating and knowing which complaint agencies need to be approached. Often, the complainant will need to approach different government agencies for one complaint.

Disability service provider from Western Australia:

Barriers to complaints:

Do not know how to make a complaint. Complaints never get made by people with an intellectual disability as they are not encouraged or know how to do so. Politics.

Factors in not making complaints:

Not enough information. Don't know how to do it. Fear of retribution. They won't be believed anyway.

Disability service provider from Tasmania:

Barriers to complaints:

The fact there are not enough advocates and lack of funding for advocates.

Factors in not making complaints:

I think it's more about 'another' thing on parents and caregivers plates and the added pressure of a complaint.

Family member of a person with disability from South Australia:

Barriers to complaints:

Communicating the issue or being able to express the concern. Being taken seriously. Filling in forms. Internet access. Anxiety. Needing support / reassurance. Knowing the process on how to do a complaint.

Factors in not making complaints:

Often it's too stressful or anxiety can be an issue, time can be an issue. Fear of upsetting the person or being refused support/ services.

Family member of a person with disability from Northern Territory:

Barriers to complaints:

Not having an advocate is the greatest barrier. Or service providers using "in house" advocates.

Family member of a person with disability from Queensland:

Barriers to complaints:

I think in regional and remote areas of Queensland, people are often frightened to make complaints because of the lack of alternative solutions or services. If there is limited availability, then they are not encouraged to complain because there is no other provider to use instead.

Factors in not making complaints:

I think that if physical or mental harm is involved, then it is definitely appropriate to stand up and complain and see the process through. However, again, people with disability and their carers/families are already under enormous strain, and many do not have the time or energy to pursue things fully.

Family member of a person with disability from Queensland:

Barriers to complaints:

Reduce and control communication. Slowing down any timely response. Disregarding medical reports.

Factors in not making complaints:

the immediate threat to the disabled persons' quality of life and their wellbeing, the lack of recognition that there is a problem or denial of such, after having communicated the issue to the service involved.

Person with disability from Queensland:

Barriers to complaints:

The independence of complaint [mechanisms]. Deal with fear of negative impact from raising a complaint.

Factors in not making complaints:

Energy to see the complaint through. Support from informal people.

Carer of a person with disability from New South Wales:

Barriers to complaints:

Not enough independent information. Being disenfranchised by power imbalance with service provider, NGO's [non-government organisations], and especially government department and private sector, so one is rail roaded.

Factors in not making complaints:

Sense that justice is possible, probable and that there is hope so that one does not take the matter into ones own hands regardless.

Disability advocate from New South Wales:

Barriers to complaints:

Untruthful information provided by staff at group homes.

Disability advocate from Victoria:

Barriers to complaints:

Service providers lie, pretend it's not their responsibility, mislay records and documents, scapegoat the complainant and add pressure, badmouthing the advocate and their agency. Threats to defund the advocacy agency etc.

Factors in not making complaints:

Potential 'costs'. Time involved until resolution (if this is even possible after the complaint is made). Pressure or indifference from coworkers or residents. Previous experiences of making complaints. Most successful complaints have been made by people who are worried for 'others', eg. assaults, thefts and abuse from staff. People also have said they don't want to complain alone, and appreciate the confidence of the advocate at their side throughout the processes.

Carer of a person with disability from Queensland:

Barriers to complaints:

Advocacy is limited and often targeted (ie taxi subsidy scheme funding) rather than being truly representative of the individuals needs. Being met with brick walls and redirection at every turn. The system doesn't seem to value complaint or learn from it. Fairly defensive.

Factors in not making complaints:

A lack of viable alternatives. Fear of further abuse or neglect. Fear of not being believed. A belief that it won't make a difference to speak out.

Person with disability from Queensland:

Barriers to complaints:

Lack of care, fear of having retribution. Many instances are available where the service provider retaliates, the support is withdrawn or changed without notice.

Factors in not making complaints:

Retribution. Time-consuming and being sent on a path with no result or any resolution. Not interested in compensation just want the complaint resolved

Family member of a person with disability from Queensland:

Barriers to complaints:

Nothing really is ever done and big organisations use scare tactics against service users.

Factors in not making complaints:

That they [do not] have a good advocate beside them.

Disability support worker from Queensland:

Barriers to complaints:

They're not listened to or their complaint is disregarded.

Factors in not making complaints:

When they aren't getting the support they're entitled to.

Family member of a person with disability from Victoria:

Barriers to complaints:

Bureaucracy covering itself only - ensuring that it is not to blame, tick and flick and leave is the norm. No real investigation done in any service as this would upset the money-making.

Factors in not making complaints:

The lack of staff care when complaining, the lack of any management support for same. The system that then denies any wrongdoing as part of its normal practice - all designed to make and save money.

Disability advocate from Western Australia:

Barriers to complaints:

Knowing that something has happened that they can complain about, and ignorance of their rights. Feeling unable to make a complaint without guidance or support. Fear of retribution. Lack of alternative service provision if complaint is or isn't successful.

Factors in not making complaints:

See above.

Disability advocate from New South Wales:

Barriers to complaints:

Services won't realise complaints policy, refuse to respond to complaints. Biased in handling of complaints and victimisation of complainant.

Factors in not making complaints:

a few enjoy complaining as a control mechanism but most complain when in a trusted supportive relationship with people who think it is ok to have a reasonable quality service and will complain if can negotiate for reasonable service

Disability advocate from Victoria:

Barriers to complaints:

Communication and understanding, as well as supporters trying to get their own agenda pushed.

Factors in not making complaints:

Having Self Advocacy skills and confidence in themselves, helps when speaking up. Fear of getting in to trouble will limit them speaking up. Being seen as a trouble maker. Previous experience of negative outcomes will limit their willingness to speak up again.

Appendix C: Advocacy and Safeguarding

DANA ran an online survey in 2015 during the consultation on the NDIS Quality and Safeguards Framework.

Survey respondents were asked to “**Select which category you identify with most strongly**” from the following list:

- Disability advocate
- Person with disability

- Carer of a person with disability
- Family member of a person with disability
- Disability support worker
- Disability service provider

A number of questions focused on the role of independent advocacy in safeguarding including its impact on safety and quality, and how advocacy strengthens or contributes to the three domains of safeguarding.

Developmental domain

Survey respondents outlined ways that advocates and advocacy organisations contribute to the developmental domain:

- *Refer people to assertiveness and rights training and value and respect people and encourage them to believe they have rights*²⁷⁹
- *Empower people with disability to exercise choice and supporting them in their decision-making.*²⁸⁰
- *Ensure that service provider practices do not exclude people with disability from their families or wider community.*
- *Assist individuals to understand their rights by providing relevant information, which includes face to face conversations, written information and assisting them to attend workshops and conferences.*
- *Making sure they have relevant information about contacts they might find helpful, providing information about the CRPD [United Nations Convention on the Rights of Persons with Disabilities]*²⁸¹²⁸²
- *Arranging access to community programs that group homes would not normally provide.*²⁸³
- *ensuring that the vulnerable person is at the centre of all decisions and consulted. By coaching and teaching throughout any process.*²⁸⁴

“Advocacy plays a vital role in the lives of people with disability and their carers/families. Advocacy supports people with disability independently of their service providers and

²⁷⁹ Disability advocate, NSW.

²⁸⁰ Disability advocate, QLD.

²⁸² Disability advocate, NSW.

²⁸³ Disability advocate, NSW.

²⁸⁴ Disability advocate, SA.

*empowers them to stand up for their rights and own wellbeing without being judged or penalised for doing so. Advocates give people with disability a voice and confidence to speak up for their rights. And encourage people with disability to achieve their goals and aspirations in a non judgemental way.*²⁸⁵

*“By being independent; offering great free workshops for people whose agenda, like them is making life better for the person with disability, not for a business venture capitalist; making the community aware of vital issues; linking families, others whose goals and ethics are the same, ie. to support families and people with disability to be able to lead safe, happy valued and productive life in the wider community.”*²⁸⁶

*“Advocates provide information and training. They have the capacity to repeat information and training for people with intellectual disabilities who may require the information a number of times. They can provide information and training in different formats, for instance plain English, and audio visuals.”*²⁸⁷

*“Independent advocacy enables people to access the information and advocacy support they require so that they feel more confident in fighting for their rights. People with disability need to know that they can access advocacy support when needed so that they can challenge decisions when necessary.”*²⁸⁸

*“Information” is also talked about in the paper as a safeguard. How that information is received is vital if the person is to be able to make good use of it in their decision making. Advocates spend a lot of time assisting people with disabilities to access, interpret and understand information in order make informed decisions. This role is not fully appreciated.*²⁸⁹

- *“Ensuring that clients understand all information provided by the NDIA, including the NDIS process, planning for their Plan and their NDIS Plan.*
- *Encouraging liaison between the NDIA and the participant in a face-to-face meeting which gives the person with the opportunity the chance to discuss their understanding of the Plan and clarify any questions/concerns that they may have. This has led to positive outcomes occurring, which if left may have escalated to that participant making a formal complaint.*
- *Assistance with helping the participant interpret their Plan and what is expected of them. e.g. explaining that the participant needs to link with an organisation who*

²⁸⁵ Disability advocate, NSW.

²⁸⁶ Carer and family member of a person with disability, NSW.

²⁸⁷ Disability advocate, VIC.

²⁸⁸ Disability advocate, WA.

²⁸⁹ Disability advocate, TAS.

*provides support coordination or a therapy service to complete a therapy assessment.*²⁹⁰

“Advocacy provides clients with an end point, a place to learn from each other as much as from trainers. It provided a place to share their stories and experiences.

*Advocacy strengthens a client’s self advocacy skills in standing up for their rights and having a comprehension of processes.*²⁹¹

*“A client can come to an advocate with a single issue and through discussion it is recognised that there are social issues such as isolation. Information is provided to the client relating to available social activities in the area, discussion is held about the client's preference and assistance is given to engage them in that activity if they wish. The same is true of training, employment or group activities. Advocates take time to listen and recognise possible areas needing assistance”*²⁹²

*“People develop an understanding and the confidence to manage their wellbeing and prevent harm. They are 'armed' with the knowledge they need when dealing with the system and services.”*²⁹³

*“Client and staff training are available from advocates, this is especially important as we provide an example of how to speak to people with disability, how to give them information for them to choose, how to listen etc. This can be a very good trigger for someone to take guidance from”*²⁹⁴

*“If we teach the clients to self advocate and show them the skills along the way, the client is going to be, are aware of safety and certainly prevents abuse if you are educating them along the way in what they do not need to tolerate. Education is key and we do that also.”*²⁹⁵

*[VIC Advocacy organisation] “has been involved in the training of workers in the welfare and disability sector. We are frequently asked to do training sessions with students where we teach them about advocacy and inform them of how to access our service and the situations under which they could and would be encouraged to access our service. I do not know of any training providers in this region who have not included us in their curriculum.”*²⁹⁶

²⁹⁰ Disability advocate, WA.

²⁹¹ Disability advocate, NSW.

²⁹² Disability advocate, NSW.

²⁹³ Family member of a person with disability, QLD.

²⁹⁴ Disability advocate, VIC.

²⁹⁵ Disability advocate, NSW.

²⁹⁶ Disability advocate, VIC.

Preventative domain

Survey respondents outlined ways that advocates and advocacy organisations contribute to the preventative domain:

“The presence of an advocate in a person’s life has a protective effect. Others know that someone is watching and their behaviour changes accordingly. It is a powerful difference.”²⁹⁷

“It is an important and often essential safeguard for the vulnerable person in ensuring they are safe from abuse neglect and harm. Often improves with the presence of an advocate.”²⁹⁸

“Sometimes, unfortunately, when some people know an advocate is around the person, behaviours change. At times people get 'threatened with an advocate', staff responses change, etc. An advocate can quote rules, policies, standards, complaints systems available etc, but this rarely makes people safe. Key workers and service providers can be assisted by the advocate to recognise existing risks, and ask, suggest or negotiate preventive matters. Bottom lines are for people to understand their responsibilities, and actually have the skills and common sense to carry them out. Evidence of advocacy and successful preventions are hard to prove. (He didn't choke, he hasn't died)”²⁹⁹

“Advocates understand the UNCRPD [United Nations Convention on the Rights of Persons with Disabilities] in a way that the service providers do not. Advocates’ interest is in the rights of people with disabilities and not the protection of a disability support organisations risk agenda. It is essential that independent advocates and people with disabilities are in any room with decisions about the need to balance ever day risk and the need to be protected from foreseeable abuse and neglect.”³⁰⁰

“Helping to give people a voice and empower them to exercise choice and autonomy helps to reduce incidences of challenging behaviour (that can escalate to result in professed need for imposition of restrictive practices).”³⁰¹

“People who are vulnerable often cannot "read the signs" of issues arising. Advocates often can, especially if they have known the person, their circumstances and significant others for some time. Advocates can then put things in place to support the person to avoid some crises. Eg. Person is still living at home with elderly parents who are not well. The advocate can

²⁹⁷ Disability advocate, ACT.

²⁹⁸ Disability advocate, SA.

²⁹⁹ Disability advocate and family member, VIC.

³⁰⁰ Disability support worker, WA.

³⁰¹ Disability advocate, QLD.

influence and facilitate the setting up of plans for when life will inevitably change for the person and parents.”³⁰²

“Advocates can speak with the service provider or the department and offers solutions to the problem, offering advice and information about alternatives. Advocates can link to other supports/services to remedy a shortage of supports, or can provide education and advice about ways the person's rights must be respected and upheld. Sometimes this is merely reporting on wrongdoings, or a lack of appropriate supports and opportunities that Department of Disability Services will fund, or finding appropriate housing, or another compatible co-tenant.

Some advocates will provide information and advice, including advocacy strategies, so that the person and or their family members can make their own complaint. In other instances, advocates will talk with the person and determine what the issues are, and will speak, write and act on their behalf both in consultation with the person about their wants and wishes, or on their sincerely perceived best interests.

The same experiences in advocacy and the inclusion of advocacy efforts educates the person about the kinds of appropriate relationships with support workers, tenants, friends and associates. ...Advocacy efforts also inform service providers about 'right relationships' and their own responsibilities and obligations to duty of care and respect for the persons rights.”³⁰³

“Advocate for people not to be placed in unsafe situations, eg. people living in hostels, who may be sharing their bedroom with known felons, people being required to live in shared support accommodation where there are behaviours of concern and restrictive practices in place; ensuring families have access to visiting sons and daughters when they are living in group homes, hostels or locked facilities; ensuring that individuals have access to legal system where necessary; ensuring that services have developed in consultation with the person and family and advocate, individual plans that include risk management strategies in relation to health care and emergency situations”³⁰⁴

“If individuals know they can speak up or have help to do so, then their wellbeing and in turn, safety, is going to be better. Knowing that you have the right to have a say about the type of service you receive hopefully creates a culture of accountability by an individual to speak up and also by support staff to do a good job.”³⁰⁵

[NSW Advocacy organisation] “have escorted [John] to doctors appointments, have inspected his living conditions, made suggestions relating to his privacy in the house,

³⁰² Disability advocate, SA.

³⁰³ Family member of a person with disability and disability advocate, QLD.

³⁰⁴ Disability advocate, QLD.

³⁰⁵ Disability advocate, VIC.

arranged for staff at the house be more responsible in overseeing to his everyday needs, and contacted his place of work, opening the door to communications with everyone connected with [John].”³⁰⁶

*“Advocates are increasingly being involved in assisting NDIS participants through planning, service selection and plan review processes. This helps participants to be able to identify and articulate their needs and wishes, which in turn improves the likelihood that the resulting plan and supports will be an accurate reflection of what the person wants. This not only is good for the participant, it is also a more efficient way of developing plans. It also reduces the likelihood of problems then occurring due to poor planning or support allocation which is a preventative safeguard.”*³⁰⁷

*“I am the advocate for an intellectual disabled person. I monitor the medications he receives to ensure it is appropriate and I also monitor the services that provided for him by the group home. I consider it very important that he has someone who advocates for him.”*³⁰⁸

*[Independent advocacy] “contributes to [minimum] standards guidelines being adhered to, supports consumers with questions/concerns & contributes transparency & accountability of service providers. Feedback shared by pwd [person with disability]/ family is that having an advocate present changes the quality of communication & interaction with the service providers & supports actions on agreed outcomes.”*³⁰⁹

*[Access to independent advocacy] “Gives the person the confidence to complain as they know they are not standing alone. Puts service providers on notice to ‘do the right thing’.”*³¹⁰

*“The quality of the services that people receive [is] higher when independent advocates become involved as they know exactly what their clients’ rights are and can step in and assist the client to access quality services, reminding services of their obligations under the DSS [Department of Social Services] and assisting them where there may be confusion as to whether actions are acceptable or not, for example, unintentional restrictive practices such as locking rooms up that the service provider may not realise is a restrictive practice.”*³¹¹

*“Advocates can be approachable for services to engage them to encourage and value complaints for service improvement in both an active and proactive approach to incidents. Advocates can assist services by recommending possible methods that can evaluate current processes”*³¹²

“From my experience, some organisations “walk the walk” as well as “talk the talk” and will recognise that “suggestions for improvement” or “complaints” can provide them with a

³⁰⁶ Carer of a person with disability, NSW.

³⁰⁷ Disability advocate, TAS.

³⁰⁸ Disability advocate, NSW.

³⁰⁹ Disability advocate, NSW.

³¹⁰ Disability advocate, WA

³¹¹ Disability advocate, NSW.

³¹² Disability advocate, NSW.

positive way to ensure that safeguards are put in place so that the current mistakes are not repeated - but this tends to be rare!”³¹³

“Although most service provider workers will say that they “advocate” for their clients, many do not even consult their client as to their wants and needs. They make decisions for them. That is when the client comes to us.”³¹⁴

[access to independent advocacy] *“is very important, I am unable to oversee the everyday workings in the group home because of distance and aging, the Advocacy are my eyes and ears. Their help has been a blessing, they have saved my sanity, I have been fighting for forty years for my friend. It has only been since Advocacy have been helping that I can relax and not worry about what will happen to my foster-son when I can no longer help him.”³¹⁵*

“Advocacy ensures that people are aware of shonky practices and providers in the community. This means that less people and families are taken advantage of and come to harm.”³¹⁶

“Helps people to understand and resolve things simply before it escalates and ‘bridges’ to facilitate this process and prevent unnecessary upset and turmoil for all stakeholders.”³¹⁷

“Advocates assist complainants clearly put forward their concerns and preferred resolution, thus assisting in making for a smoother process. If referrals are received early, complaints can be resolved before they escalate. Most service providers know that if a person with a disability has an independent advocate assisting them then the complaint is not going to go away if they ignore it. The presence of an advocate is a major “incentive” for a provider to resolve the matter.”³¹⁸

“By helping the person to identify the issue, to confirm that there is a real issue, not a misunderstanding; also helping them to communicate their thoughts and feelings and needs to the provider to try to resolve the issue amicably.”³¹⁹

“If an advocate is retained in the early stages of an issue, good negotiation skills and an attitude that sincerely believes that their job is to increase efficiency of the complaint process

³¹³ Disability advocate, WA.

³¹⁴ Disability advocate, VIC.

³¹⁵ Carer of a person with disability, NSW.

³¹⁶ Family member of a person with disability, QLD.

³¹⁷ Family member of a person with disability, QLD.

³¹⁸ Disability advocate, TAS.

³¹⁹ Disability advocate, VIC.

for both service and client, generally leads to early and positive resolution through communication and openness.”³²⁰

“We de-escalate issues often by working out the real underlying problem and examining the most simplistic solution rather than letters to the minister, the queen and the pope. We advise PWD [people with disability] on the best avenue to satisfy their problem and assist them down this path if needed.”³²¹

[Advocates] “Give us better understanding of what NDIS can do to work with our loved one, that they are not just a name without a face.... [NSW Advocacy organisation] have given me a reason to go on loving and caring. Because their support and care gives hope and courage. With encouragement we won't lose the strength to carry on. The battle was almost lost because of isolation and secrecy. Open the doors and make everybody accountable for their actions. We have had negative responses to our questions for too long. Speak to us in a language we understand. Show us what signs to watch out for.”³²²

Corrective domain

Survey respondents outlined ways that advocates and advocacy organisations contribute to the corrective domain:

“Advocates can assist a person with a disability to list their concerns and see how these match service standards, human rights indicators etc, [Advocates] can make referrals to specialist Legal Advocates. Advocates can validate what is being alleged about a person with a disability by gathering third party evidence etc. I advocated for an Aboriginal man with a disability who was subject to a forensic order. His treating doctors had written their Clinicians Reports to the Mental Health Tribunal that he was not allowed back to live in his remote community. I wrote to the Mayor of the Community and obtained evidence that this was not true, they simply wanted him to receive the necessary support to live in the community. I advocated for a service provider to be sourced who could provide the necessary support in his community. He returned home to his community after a permanent absence of over 10 years.”³²³

“A citizen's advocate in [QLD city] questioned a physician who had authorised a "Do Not Resuscitate" sign on the bed of a nursing home resident who had disabilities. When challenged, he immediately withdrew the sign and showed great deference to the advocate.

³²⁰ Disability advocate, NSW.

³²¹ Disability advocate, NSW.

³²² Carer of a person with disability, NSW.

³²³ Disability Advocate, QLD

*It was clear that this doctor was worried he would be held to account for his decision which was done without any consultation with the advocate.*³²⁴

*“Advocacy can strengthen or contribute to the corrective domain... as it can help address issues and barriers quickly and where issues and barriers have occurred warranting a complaint.”*³²⁵

*[VIC Advocacy organisation] “has been called on to be part of action in response to an incident and to give advice to workers to avoid a recurrence or to assist to correct a way of working or thinking in relation to people with disability.”*³²⁶

*“because they have the knowledge to contact the right people and Department who can deal with whatever a situation is in need of attention. They deal with the problems (without the emotional drama of a family or carer) with compassion and sensitivity.”*³²⁷

*“The strong, “traditional” role of advocates has been in supporting people to raise complaints and to have those complaints resolved. This is a corrective safeguard.”*³²⁸

*“many occasions advocacy is called in after the events have occurred. Advocacy assists to immediately safeguard the person, ensure recordings are made, statements taken, policies are reviewed and acknowledgements of events made. Options for immediate and longer term resolutions are canvassed with the person and agency / individuals involved. In practice this has meant immediate removal of staff / reports to police / removal of covenants / convene meetings of parents or residents re: issue etc. Increased monitoring mechanisms into place, contact lists spread around and review times set and kept.”*³²⁹

*“I think we hold organisations and services accountable and this makes them look at their own policies around clients with disabilities and if they could improve them. If they do not have updated policies around new legislations that are relevant, and human rights guidelines, then they can work and create new policies that are inclusive and respect clients with disabilities.”*³³⁰

*“Advocates follow up on complaints and monitor outcomes.”*³³¹

³²⁴ Family member of a person with disability and disability advocate, QLD.

³²⁵ Person with disability, NSW.

³²⁶ Disability advocate, VIC.

³²⁷ Carer of a person with disability, NSW.

³²⁸ Disability advocate, TAS.

³²⁹ Disability advocate and family member, VIC.

³³⁰ Disability advocate, VIC.

³³¹ Family member of a person with disability, NSW.

“An advocate can ask for follow up action to any complaints that have been made, verbal and written reports to be made and choose to take further actions to appeal or seek formal review of decisions. An advocate can take the matter to the public arena and an advocate can request apologies and compensation be provided to the person with a disability. The 'corrective domain' needs independent advocates in order to function effectively.”³³²

“For People with disability, the Queensland experience has been no choice in regards to what service they use, where they live, who they live with, and how they spend their time during the day/night. The manner in which services have been delivered can result in breach of human rights - Access to ways of enforcing those rights, while readily available to many others in society, may be restricted or denied to people with disabilities... Advocacy assists the person to question the service provider, being informed of policy and procedures that the service provider should be following, monitoring the day-to-day competence of the service by bringing up issues of neglect and abuse with the appropriate authorities.”³³³

“ensuring individuals have access to lawyers, appropriate decision making support, making sure individuals are not left in abusive situations, making sure that instances of abuse and neglect are reported and acted upon. Supporting people through the anti-discrimination processes”³³⁴

“Even though Safeguards against Abuse and Neglect exist in legislative provisions drafted with the intention of safeguarding vulnerable persons and persons with a disability from abuse and neglect in different circumstances, some go further and seek to promote the human rights of persons with a disability. One of which is the right to live a good life in the community. Whilst legislative intention is commendable, none of the above mentioned laws have “teeth” and do not protect a person with a disability or facilitate good lives for them in the community. Grassroots advocacy, of the type that [QLD Advocacy organisation] provides, has the ability to observe and challenge human rights abuse and neglect, when government actors and service provider are unable or unwilling to do so”³³⁵

“Take issues directly to the department, particularly those that are a common occurrence. Discuss same in an open forum such as the service providers forum.”³³⁶

“advocacy will take the matter up wherever necessary. advocacy contributes to the discussion in regard to debriefing the situation and solving the problem in the vulnerable person's best interests. advocacy remains vigilant in regard to the person's best interests”³³⁷

³³² Family member of a person with disability and disability advocate, QLD.

³³³ Disability advocate, QLD.

³³⁴ Disability advocate, QLD.

³³⁵ Disability advocate, QLD.

³³⁶ Disability advocate, QLD.

³³⁷ Disability advocate, SA.

“Independent advocacy ensures that complaints about quality of service gets addressed as directed by the individual with disability. They get followed through until resolved and escalated, if necessary, until resolution. Without independent advocacy, [services] 'smooth' things over with the client - we see this time and time again - without actually addressing the issue. Without independent advocacy, there is a lack of reporting back to the client and the client is also vulnerable to reprisals by individual support staff if the quality of service directly relates to them.”³³⁸

“Independent advocacy is typically the only way that service-users and their families have success challenging poor practices of service providers. Many people supported by advocates have already tried all of the complaints mechanisms available to them, and have still not achieved a positive result. Many organisations, and even government departments, are much more proactive in solving problems when an advocate is assisting the person making a complaint.”³³⁹

“even for people without disability, one needs special knowledge and skills to successfully navigate the complaint system. I had been an advocate for 26 years in NSW and each case is a learning experience. Even with my experience and high qualification, each case is difficult and requires 100 percent commitment to the cause.”³⁴⁰

“Advocates research thoroughly the issue at hand. They discuss the issue with people with disability or the support worker/interpreter. Advocates negotiate with the other party and try to resolve the issue by communicating with the other party. [CASE STUDY] Two people with disability live adjacent to each other in a social housing compound. One person with disability [Jane] was being accused of bullying by the other person with disability who uses wheelchair for mobility [Joan]. An advocate for [Joan] asked the support provider of [Jane] for a meeting with [Jane], her support provider, [Joan] and the advocate. The advocate informed the meeting that it is a serious offence to bully and harass a neighbour and informed everyone that there are consequences for this unpleasant behaviour. The advocate facilitated for [Joan] to tell [Jane] what actions she felt were bullying and harassment. [Jane] admitted and promised [Joan] and everyone in the meeting that she will not do those actions that [Joan] felt were bullying actions.”³⁴¹

“Advocate assist pwd [person with disability] to know if the issue requires a complaint. A better understanding, more information, someone on their side who they can trust explaining an issue, can assist to resolve matters. If the matter can be the subject of a complaint, the pwd can be fully informed as to the process, outcomes and decide whether or not to proceed. Negotiation can be done by an advocate, but involving the pwd to help resolve it themselves.

³³⁸ Disability advocate, WA.

³³⁹ Disability advocate, VIC.

³⁴⁰ Disability advocate, NSW.

³⁴¹ Disability advocate, NSW.

If negotiation is unsuccessful, the pwd can decide whether to proceed to a formal complaint or not. Advocate can explain any offers from service provider to resolve an issue. Pwd can fully participate in any resolution. Outcomes in which the pwd has participated are usually the most successful and the pwd and service provider relationship can be preserved.”³⁴²

“Where the advocate and vulnerable person know each other and have a good relationship, the person is likely to talk through issues with the advocate. The advocate may also pick up on small variations in the person's behaviour or mood that suggest an issue is at hand. Knowing the person also means that the advocate may be familiar with the person's cycles of behaviour or crises. All these things mean that the advocate can sometimes pick up on issues before they become problematic. As people get used to the involvement of an advocate, and see their issues resolved, they are more likely to seek out solutions before they feel the need to complain.”³⁴³

“Being free of conflict of interest is key here to ensuring advocates can confidently challenge with and on behalf of people who are vulnerable. The ideal is that the advocate seeks to rectify situations by conversation, creativity and suggestions. Only if a situation cannot be resolved in any other way, should formal mechanism be employed.”³⁴⁴

“Advocates give people with disabilities information so they can advocate on their own behalf if possible. They give people information so they can make a choice about the next steps to take, and talk to them about consequences of directions they may take. They can liaise with service providers, they can attend meetings to support people with disabilities. They can suggest ways to work to support the person with disability; the ideas may be taken up by the disability service provider”³⁴⁵

“Research the complaints procedure, pass on the information, go over the information with the client if required. Answer any questions that the client may have. Allow time to think about the process.”³⁴⁶

“By informing them of who they can make a complaint to and assisting them, or do the paperwork for them, depending on their ability. Sometimes it might start right at the beginning by actually informing them that they have the grounds to make a complaint.”³⁴⁷

“We firstly advise them of their rights and encourage to strive for better. Then we would mediate with the services and make sure we have good relationships with them in the first place so they already feel they can work with us on all different cases. This is important in

³⁴² Disability advocate, WA.

³⁴³ Disability advocate, SA.

³⁴⁴ Disability advocate, SA.

³⁴⁵ Disability advocate, VIC.

³⁴⁶ Family member of a person with disability, WA.

³⁴⁷ Disability advocate, VIC.

small rural communities, networking. We emotionally support the client with the process as well as assist them to try to feel confident, and make them independent in it, so they feel more capable next time if they have an issue, to know the process and what they can achieve if they stay persistent and believe they deserve better. We also educate people in the community like doctors, community health, neighbourhood centres etc. to make sure people know there is support in an advocate in their community and with assistance can make sure they can complain without fear or repercussions.”³⁴⁸

“[Jane] was moved from the service and placed in respite while the above issues were being investigated. The Police were asked to investigate the injuries that [Jane] received while under the care of the service provider. The police interviewed all staff, however, no one could account for [Jane]’s serious injuries, despite the fact that she has 24-hour care. All the workers reported that they did not know what happened to [Jane]. As [Jane] has very limited verbal communication she was not able to tell the police what had happened. The police found that they were not able to press criminal charges as they could not obtain sufficient evidence. [QLD advocacy org] made a complaint to Communities and Disability Complaints Unit and we have been advised that the complaint regarding [Jane]’s injuries has been referred to the Department’s Compliance Unit for investigation due to the potential criminal nature of the matter. [QLD advocacy org] also made a complaint to Communities and Disability Complaint Unit about the breaches to [Jane]’s privacy and the illegal use of chemical restraint. Both of these complaints were substantiated, and the service has undertaken to develop and implement strategies to ensure that the service complies with the relevant Acts. [QLD Advocacy Org] requested that the Public Trustee undertake a full financial audit of [Jane]’s finances and as a result the service has been ordered to pay several thousand dollars back into [Jane]’s account. [QLD advocacy org] will continue to advocate for [Jane] to ensure she remains safe and is able to access appropriate support in the community.”³⁴⁹

“After initially meeting or speaking with the person with disability, family or carer is about the issue or barrier, if it is decided to undertake a complaint to get it addressed, the advocates and advocacy organisations support people with disability to make complaints by undertaking the preliminary research and making enquiries. This would include the most appropriate complaints and appeals process. Advocates and advocacy organisations can also provide appropriate information and referral, particularly if there is a need for pro bono or community legal services to address the complaint of a serious nature or if the initial complaint is unable

³⁴⁸ Disability advocate, VIC.

³⁴⁹ Disability advocate, QLD.

*to be conciliated through a formal Federal or State complaint process such as the DDA [Disability Discrimination Act 1992] or a State discrimination act.*³⁵⁰³⁵¹

*“the Advocates, who work with us, have helped by going to doctors appointments, visiting the Group home, keeping everyone concerned with [John] communicating and making sure that everything that needs to be done, is. They have the know-how and experience to handle each situation without the drama.... With knowledge and experience that they have achieved over the years, helping many families. They know that a lot of families have similar problems. The Advocates listen, acknowledge without judgement, and give support when we need it the most.”*³⁵²

*“be there when needed. Assist in writing and lodging papers, or involve another agency to assist (eg. legal) Pre and post discussions, planning, strategising, ensuring all necessary other supports are in place and ready for the person involved, assist the person to pace themselves, agree on how they want to handle the processes and what role they wish the advocate to take etc, be there for the long haul and celebrate or commiserate at the conclusion of the complaint. Also useful to put stuff in place as contingency for results.”*³⁵³

*“Walking the path with the vulnerable person to ensure their rights are not overlooked, but also that they are protected in their vulnerability by interpreting the issue for the person; translating for the person the processes; reassuring them; being a spokesperson when the person cannot speak for him/herself; ensuring that the person is heard effectively and taken seriously; coaching the person through the process; teaching as required; being consistent; ensuring that the person is not being stereotyped or that their reputation is not clouding the process; supporting better decision making; being available as the person needs.”*³⁵⁴

[QLD Advocacy Org] “advocated for a man that was tied to a kitchen table by his service provider for hours each day for a number of years. Restrictive practices were not in place or applicable. The Disability Services Act 2006 - s19 states that people with a disability have the same human rights as others and (c) live lives free from abuse, neglect or exploitation. DCCS [Disability and Community Care Services] officers were aware and did nothing. Managers of the support service did nothing. The Community Visitor was requested to view this person in his home and even though s223 of the Guardianship Act states that the purpose of the Community Visitor is “providing Community Visitors for visitable sites is to safeguard the

³⁵¹ Person with disability, NSW.

³⁵² Carer of a person with disability, NSW.

³⁵³ Disability advocate and family member, VIC.

³⁵⁴ Disability advocate, SA.

*interests of consumers at the visitable sites". The Community Visitor found nothing amiss. When finally the police were asked to investigate whether a crime was taking place, they concluded that s355 of The Criminal Code, Deprivation of liberty of a person who unlawfully confines or detains another in any place against the other person's will, or otherwise unlawfully deprives another of the other person's personal liberty, is guilty of a misdemeanour, and is liable to imprisonment for 3 years, did not apply to tying a disabled person to a table. No one was charged. Only the continued work by an advocate was able to resolve this situation. What is often seen as abuse or a crime for an abl- bodied person is not seen by government authorities as a crime when it is done to a person with a disability."*³⁵⁵

*"When the service provider goes to QCAT to request that restrictive practices be implemented, the person with disability is often not at the table. This is due to a number of reasons. The individual advocate is often the only person who can argue against the restrictive practices and lobby for other solutions. An example is where an individual does not have adequate funding to live alone and therefor live in a group situation that activates and escalates the person's behaviours of concern. The only way the service provider can manage the situation within the available funding is to 'contain' or to 'seclude'. The least restrictive option would be to let the person live on his/her own with appropriate funding. The advocate's role would be to ensure that that positive behaviour support plans are followed and incidents are appropriately recorded; reviews are undertaken; and that staff have proper training to manage the situations that may arise. Advocates have the educative role to ensure that CRPD [United Nations Convention on the Rights of Persons with Disabilities] articles and conventions are complied with."*³⁵⁶

³⁵⁵ Disability advocate, QLD.

³⁵⁶ Disability advocate, QLD.