

Chapter 7

Advocacy

7.1 This chapter examines the role and challenges of disability advocacy in preventing and responding to violence, abuse and neglect against people with disability.¹

7.2 This chapter highlights the importance of formal, informal and self-advocacy models of advocacy, in assisting people with disability to identify, report and respond to incidents of violence, abuse and neglect.

7.3 The Victorian Advocacy League for Individuals with Disability Inc. (VALID), defines the roles of advocacy as to:

- address discrimination
- empower individuals through information, support & knowledge of their rights
- for community education
- increase the quality of life of individuals and their families
- make services accountable
- address inequity of service provision.²

7.4 VALID further defines the types of advocacy as:

- **Individual Advocacy:** to seek a solution with and for people with disabilities to their particular problems or needs, so as to enhance their rights and dignity.
- **Systemic Advocacy:** to influence the 'system' (e.g. the policies and procedures of agencies/governments) to change in response to people with disabilities and their families/carers needs.
- **Self Advocacy:** is about people with disabilities/ families & carers, speaking up for themselves. Self-Advocacy services assist consumers to develop or maintain the personal skills and self-confidence necessary to enable them to represent their own interests in the community.
- **Citizen Advocacy:** Citizen Advocacy services recruit and support individual volunteers from the community to assist i) persons with disabilities, or ii) the families of, and other persons who provide care for and assistance to, people with disabilities to represent their interests in day to day life and the community.

1 See: Terms of reference (g).

2 Ms Christine Scott, *Advocacy*, <http://www.valid.org.au/advocacy.htm> (accessed 9 November 2015).

- **Group Advocacy:** Group advocacy services facilitate community organisations to represent the interests of groups of persons with disabilities and/or their families/carers.

7.5 As noted above, the committee has also considered the delivery of formal advocacy services, that is services specifically funded to deliver one or more of these advocacy models for people with disability to enable them to 'participate in the decision making processes that safeguard and advance their human rights'.³ A key form of funding is the National Disability Advocacy Framework (Advocacy Framework).

National Disability Advocacy Framework

7.6 In 2008, Australian, state and territory disability ministers endorsed the Advocacy Framework. The Advocacy Framework sets out principles to guide the provision of advocacy services with people with disability to achieve the long-term goal that:

People with disability have access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation.⁴

7.7 In June 2015, the Department of Social Services (DSS) launched a review of the Advocacy Framework in anticipation of the full roll out of the National Disability Insurance Scheme (NDIS). DSS sought submissions addressing the principles, outcomes and outputs of the Advocacy Framework and any changes required.⁵ The committee notes that the outcomes of this consultation process had not been published prior to the conclusion of this inquiry.

National Disability Advocacy Program

7.8 The Australian Government provides funding to disability advocacy services across all advocacy models at the state and local government level through the National Disability Advocacy Program (Advocacy Program). The Advocacy Program aims to provide people with disability 'access to effective disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling community participation'.⁶

7.9 DSS submitted that the Advocacy Program:

3 DSS, *National Disability Advocacy Framework*, p. 2, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/national-disability-advocacy-program/national-disability-advocacy-framework> (accessed 22 October 2015).

4 DSS, *National Disability Advocacy Framework*, p. 3.

5 See: DSS, *Discussion paper: review of the National Disability Advocacy Framework*, June 2015, <https://engage.dss.gov.au/ndaf-2/> (accessed 22 October 2015).

6 Department of Social Services, *National Disability Advocacy Program*, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/for-people-with-disability/national-disability-advocacy-program-ndap> (accessed 22 October 2015).

...funds agencies to provide advocacy that works to uphold the rights and interests of people with all types of disabilities, by addressing instances of discrimination, abuse and neglect. This can be on a one-to-one basis, with families, by addressing legal aspects or through systemic advocacy.⁷

7.10 In 2014-15, DSS will provide around \$16.5 million under the Advocacy Program to 59 organisations across Australia, DSS noted that the Australian Government, with the states and territories, are currently reviewing the Advocacy Program to determine 'the elements of advocacy that will be funded by the NDIS and how it will align with services delivered under the Advocacy Program.'⁸

7.11 In its submission to the review of the Advocacy Framework, the Australian Cross (Disability Alliance) Disability Alliance noted that the Advocacy Program is 'strengthened' by including all models of advocacy. However, the Disability Alliance highlighted that the Advocacy Program is 'critically under resourced' and urged 'significant investment to all Advocacy Program models of advocacy' to deliver equitable access and representation of issues and to match the increased demand for advocacy anticipated under the NDIS.⁹

7.12 The committee also heard concerns about the financial impact of compliance measures imposed on advocacy organisations funded under the Advocacy Program. For example, Advocacy for Inclusion recommended removing the Advocacy Program 'compliance burdens':

We have an extremely onerous compliance system of external annual audits. We are forced to spend thousands of dollars each year from our unindexed funding on auditors, which for Advocacy for Inclusion equated to 6 weeks' [sic] pay for a front line Individual Advocate this year. However, there is no funding support to keep up with the increasing demand for disability advocacy at this time of great change and reform. This is a significant barrier to efficient and effective use of advocacy funding to promote the rights of some of the most marginalised members of the community.¹⁰

7.13 The Disability Advocacy Network Australia (DANA) criticised recent data released by DSS on the Advocacy Program that indicates that only three per cent of issues managed by advocacy services were related to abuse. DANA suggested this figure is 'much too low' and indicates that advocacy services funded under the Advocacy Program are not reaching the most vulnerable:

...it does not give you the full picture. It only touches on the people who manage to get through that process, and that will mainly be people who are

7 DSS, *Submission 104*, p. 27.

8 *Submission 104*, p. 27.

9 Australian Cross Disability Alliance, *Submission to the Review of the National Disability Advocacy Framework*, 31 July 2015, pp 2–3, answer to question on notice, 27 August 2015 (received 8 September 2015).

10 Advocacy for Inclusion, *Submission 83*, p. 32.

more articulate, who have more support and who have strong families who will help them. It will not be the people who are the most vulnerable.¹¹

Australian Government funded advocacy services

7.14 The Australian Government also provides funding directly to advocacy peak bodies to provide systemic advocacy services. In February 2015, DSS announced direct funding for five advocacy organisations:

- People with Disability Australia;
- Children with Disability Australia;
- First Peoples Disability Network;
- National Ethnic Disability Alliance; and
- Women with Disabilities Australia.

7.15 DSS submitted that these organisations have been funded to:

...work independently on behalf of their members, and collaborate on national and common issues as the National Cross-Disability Alliance (the Alliance), focusing on improving the lives of all people with disability. The Alliance will provide the Government with practical advice to help improve policies and legislation impacting people with disability across Australia.¹²

7.16 At the 2015 Budget Estimates, DSS clarified the relationship between the Disability Alliance and the Advocacy Program, noting that data on systemic advocacy issues collected by the Advocacy Program is shared with the Disability Alliance 'to further support the Alliance in contributing to government policies and reforms impacting people with disability, their families and carers'.¹³

7.17 The committee notes that its previous inquiry into the 2014 DSS tendering process heard concerns about the channelling of advocacy funding into national peak bodies, and the impact on smaller, specialised advocacy services, many of which were defunded. Some advocacy organisations that lost funding as a result of the tendering process 'expressed concern about what they perceived as the government's diminished regard for their role'.¹⁴ The inquiry recommended:

11 Ms Mary Mallett, Chief Executive Officer, Disability Advocacy Network Australia (DANA), *Committee Hansard*, Canberra, 21 August 2015, p. 10.

12 DSS, *Submission 104*, p. 27.

13 Answers to Questions on Notice, Social Services Portfolio, Budget Estimates 2015-16, 4-5 June 2015, Question SQ15-000663 (received 22 June 2015), http://www.aph.gov.au/Parliamentary_Business/Senate_Estimates/claccte/estimates/bud1516/Social%20Services/index (accessed 27 October 2015).

14 Senate Community Affairs References Committee, *Impact on service quality, efficiency and sustainability of recent Commonwealth community service tendering processes by the Department of Social Services*, Final Report, September 2015, p. 40.

...that advocacy support be considered a vital component of community services in future funding arrangements and is given appropriate weighting in funding assessments.¹⁵

National Aged Care Advocacy Program

7.18 In addition to disability specific advocacy, the Australian Government also funds the National Aged Care Advocacy Program (NACAP) to provide 'free, confidential advocacy support and information to consumers or potential consumers of Australian Government subsidised Home Care Packages and residential aged care services'.¹⁶

7.19 There are nine community-based NACAP organisations operating nationally: one in each state and territory and two in the Northern Territory. DSS submitted that in 2013-14, services under the NACAP undertook more than 3 400 advocacy cases, handled more than 4 400 general enquiries, and provided over 1 400 face-to-face education sessions. NACAP organisations also received an additional 20 per cent in funding to June 2015 to 'meet an identified unmet demand for advocacy services, particularly in rural and regional areas of Australia'.¹⁷

7.20 DSS submitted that the Australian Government is currently undertaking a review of Commonwealth aged care advocacy services to inform the government on how individual advocacy services can best support aged care consumers to:

- effectively interact with the aged care system;
- better transition between service types; and
- be empowered to apply informed decision making and actively exercise choice.¹⁸

State and territory funded advocacy

7.21 In addition to Australian Government funding, states and territories also provide funding to advocacy organisations for particular advocacy services. The Productivity Commission (PC) reports that in 2013-14 across jurisdictions, Australian, state and territory governments spent \$66.3 million on advocacy, information and alternative forms of communication. This includes:

- advocacy services to enable people with disability to increase their control over their lives by representing their interests and views in the community;
- information services to assist people with disability, their carers, families and related professionals accessing information about disabilities, specific and

15 See: Recommendation 7, *Impact on service quality, efficiency and sustainability of recent Commonwealth community service tendering processes*, p. x.

16 DSS, *Submission 104*, p. 28.

17 DSS, *Submission 104*, p. 28.

18 DSS did not indicate the timeframe for this review to be completed. DSS, *Submission 104*, p. 28.

mainstream services and equipment; and promote the development of community awareness; and

- alternative forms of communication for people who are, by reason of their disability, unable to access information provided in standard formats.¹⁹

7.22 According to the PC, expenditure on advocacy services represents approximately one per cent of the \$7.0 billion spent by Australian, state and territory governments on disability services in 2013-14.²⁰ The total expenditure on advocacy services for 2013-14 across jurisdictions is outlined in Table 7.1.

Table 7.1: Real government direct service delivery expenditure on advocacy, information and print disability services, 2013-14 (\$'000)

Year	NSW	VIC	QLD	WA	SA	TAS	ACT	NT	C'th	Total
2013-14	11 461	8 867	14 869	6 456	1 721	2 481	1 237	429	18 753	66 274

Source: Productivity Commission, *Report on Government Services 2015*, Table 14A.10.

7.23 As Table 7.1 highlights, the level of funding for advocacy services differs across jurisdictions. For example, according to the Victorian Ombudsman's report, the Victorian Department of Health and Human Services funds 24 advocacy organisations and two resource units. In 2013-14, the Victorian Government spent \$4.8 million on advocacy, including \$1.59 million for individual advocacy.²¹

Importance of formal advocacy

7.24 Overwhelmingly, submitters and witnesses highlighted the critical role of independent advocacy in the quality and safeguarding framework for people with disability to assist in identifying, reporting and responding to incidents of violence abuse and neglect.²² Ms Mary Mallett, Chief Executive Officer (CEO) of DANA, told the committee that 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.²³

19 Productivity Commission (PC), *Report on Government Services 2015*, Chapter 14, p. 14.6.

20 PC, *Report on Government Services 2015*, Table 14A.10.

21 Victorian Ombudsman, *Reporting and investigation of allegations of abuse in the disability sector: Phase 1 – the effectiveness of statutory oversight*, June 2015, p. 21, <https://www.ombudsman.vic.gov.au/Investigations/Investigation-into-disability-abuse-reporting> (accessed 24 September 2015).

22 See: IDRS, *Submission 128*, p. [4].

23 Ms Mary Mallett, *Committee Hansard*, Canberra, 21 August 2015, p. 9.

7.25 Evidence to the committee highlighted that people with disability who do not have 'natural support networks' or access to independent advocacy services, particularly those with intellectual disability or communication support needs, are more vulnerable to violence, abuse and neglect. Ms Christina Ryan, General Manager of Advocacy for Inclusion told the committee:

One of the things we know is that about half of the people we have worked with over time do not have natural support networks, so the expectation that some nice family member who is handy will step in is wrong. The expectation that there is access to an advocate is clearly wrong... We know that. We knock back two people for every one we can assist. We also know that people cannot rely on something falling out of the sky that is going to save them. Most people just end up in these decades-long situations that are simply unacceptable. That is just how it is. That is the life of people.²⁴

7.26 Witnesses suggested that advocates play an important role in assisting people with disability access the available complaints processes to identify and report abuse. Ms Michelle O'Flynn, Director of Queensland Advocacy Incorporated (QAI) told the committee:

A complaints process, no matter how robust or stringent, cannot possibly factor in all of the needs that the person has, and it is not going to be something that a person who is intimidated and living in fear is able to reach out for unless there is a way that they can seek assistance from someone is trusted and removed from that setting. A lot of victims are not going to feel that they can access a complaints mechanism. It trivialises the notion of abuse as a mere complaint about service delivery. How can they do that? Who will speak up for them and who can they turn to? We think that one of the things that can help those people is access to advocacy. But where do they get that? Unless they actually have a relationship with an advocate, that is not going to happen.²⁵

7.27 The committee heard many individual examples of how independent advocates have assisted people with disability in reporting and preventing abuse. Boxes 7.1 and 7.2 highlight just two case studies that highlight the important role of advocacy services in assisting people with disability.

24 Ms Christina Ryan, *Committee Hansard*, Canberra, 21 August 2015, p. 10.

25 Ms Michelle O'Flynn, *Committee Hansard*, Brisbane, 16 October 2015, p. 2.

Box 7.1: Role of advocates – Sienna's story

Ms Mary Mallett, CEO of DANA, shared the following case study with the committee that highlighted the importance of advocacy services in assisting people with disability to identify and report abuse:

Sienna lives in a regional town in Australia. She is 31; she is a young woman with autism who lives in a group home at a significant distance from her family. Sienna has what the staff call 'behaviours' when she is unsure and frustrated about things and when she is not receiving appropriate support. When the staff are busy or Sienna is having 'behaviours', they send her outside and put her in the van. The staff and the rest of the residents are inside cooking tea, having tea or whatever is happening, but Sienna is sent outside to sit in the driveway in the van. She is not locked in, but that is immaterial. She is told not to come out and so she sits there until she is told she can come out. The other residents are encouraged to do exactly the same thing, so that the staff have empowered the other residents to tell Sienna to go and sit in the van. They tell her this is the consequence of her 'behaviours'.

Sienna accepted this for a while, and it had been going on for quite a long time before the advocate got involved. She knew it was not okay, but she did not know what to do about it. She contacted the advocate after one particularly cold and rainy evening when she had been scared while sitting in the van in the dark, the cold and the rain. It scared her enough that she finally thought that she needed to do something about it. She made an appointment to see the advocate. The interesting thing about this is that Sienna is a young woman who attends the self-advocacy group—there happens to be one in that town—and so she already knew the advocate. If she did not know the advocate already, it is very unlikely that she would ever have made the move to do this. Even knowing the advocate—already having the contact—it still took her a long time to do something about it.

The advocate informs Sienna of her rights; they talk about the difference between consequences and punishment and about restrictive practices. When she asked Sienna what she wanted to do, she clearly stated that she wanted to complain but was afraid. She asked the advocate to make the complaint and act on her behalf. This was a complaint to the service provider; it was not outside of that. The advocate went to the services practice development coordinator, who immediately spoke with the staff and the residents. The other residents confirmed this was happening. She told everyone the practice must stop immediately. The advocate highlighted the need for the relevant resource team from the department in that area to be involved. They had staff training about restrictive practices and some specialised training for staff in effectively supporting Sienna. These were all acted upon and the situation is now resolved. There is a regular schedule for Sienna to report to that organisation's practice coordinator. So Sienna's life is currently okay.

Source: Ms Mary Mallett, Committee Hansard, Canberra, 21 August 2015, p. 11.

7.28 Box 7.2 highlights that advocates are particularly important for elderly people with disability with limited family supports.

Box 7.2: Role of advocates – Katrina's story

Mrs Sonia di Mezza, Deputy CEO of the ACT Disability, Aged and Carer Advocacy Service shared the following case study with the committee that highlighted the importance of advocates in assisting people with disability to report abuse:

I bring to your attention the case of a former client of mine, Katrina. She was a frail old woman in her 90s who suffered from some mobility issues and who lived in a residential aged care facility. One day Katrina went to the kitchen area of the facility to make herself a cup of coffee. While she was there, a carer approached her, shoved her in a corner and touched her in the genital region. He mocked her and dared her to complain, saying that no one would believe her and that he would be back to give her more. Katrina was shocked and devastated by this. She was afraid to go anywhere in the facility and became depressed. She told friends and family members about the incident, but they encouraged her to forget about it and not to take the matter further. One friend, who disagreed with this approach, encouraged her to contact ADACAS [ACT Disability, Aged and Carer Advocacy Service]. I helped my client to make a complaint to the management, as well as to the Aged Care Complaints Scheme. The police were informed about the situation, but they would not progress the matter further due to lack of evidence. Because she was frail, elderly, had poor eyesight and had some cognitive impairment, she was not considered to be a strong witness, and there were no other witnesses to this abuse. While all of this was happening, the carer resigned from the facility. The perpetrator managed to avoid any prosecution and potentially had the possibility of working with other vulnerable people and potentially abusing them. My client has passed away and sadly cannot talk about this incident with you. She was adamant while she lived that she wanted the abuse she had suffered to be talked about and addressed.

Source: Mrs Sonia di Mezza, *Committee Hansard, Canberra*, 21 August 2015, pp 33–34.

7.29 The Intellectual Disability Rights Service, an advocacy organisation in NSW, submitted that '[p]eople who have been victims of abuse and who have no family involvement should have access to an advocate or guardian external to the service to support them and advocate on their behalf'.²⁶

Challenges for formal advocacy

7.30 Despite the importance of independent advocacy, the committee heard there are number of challenges facing the delivery of advocacy services including:

- funding;
- independence; and
- access to institutions and residential settings.

Funding

7.31 According to the evidence, the key challenge for advocacy services is the available level of funding. A number of submitters noted that disability advocacy is

26 Intellectual Disability Rights Service, *Submission 128a*, p. 5.

'severely underfunded, unable to meet current demand, with the demand expected to at least double with the NDIS'.²⁷

7.32 As a result of the lack of funding, the committee heard that advocacy services are often limited to providing reactive services responding to abuse, and do not have capacity to assist in ongoing preventative support. VALID submitted that:

Because of the limited supply of independent advocacy, individual advocacy, including VALID's, has tended to become focused on reacting to situations of crisis or high need, and has become less available to people who need advocacy support in their day-to-day lives...without the long-term, low-level form of advocacy support, many issues that might have been easily resolved at an early stage tend to escalate and become major issues demanding our crisis advocacy response.²⁸

7.33 The lack of funding also results in many people with disability being turned away, or placed on long waiting lists for assistance. Ms Mallett told the committee:

A person who rang for advocacy in Sydney recently was told the waiting list was a year. In actual fact most advocacy organisations do not keep waiting lists, because they cannot; there is no point. If somebody is in a crisis, you either can help them or you cannot. But what is the point of putting them on a waiting list? What the organisations do is juggle: people who have a critically urgent immediate issue leapfrog in over the top of everybody else, because they have to get assistance. That is what happens.²⁹

7.34 Witnesses suggested that the lack of funding for advocacy reflects a lack of value placed on these services, including other capacity building services aimed at preventing abuse and neglect. Ms Taryn Harvey, CEO of Development Disability WA told the committee:

I think the organisations that provide advocacy can help in providing a range of other mechanisms. I do not think that advocacy is the only thing; communication is another thing. But I think if we started to value advocacy it would be a sign that we are starting to value the other things that are effective in preventing these situations and in capacity building.³⁰

7.35 Evidence to the committee supports the findings of the Victorian Ombudsman's 2015 report into reporting and investigating of allegations of abuse which found that:

...there is a critical role for advocates to assist people with disability; however, there is limited appreciation of the importance of this role, manifest in its modest funding, as well as an inherent conflict in advocacy

27 Advocacy for Inclusion, *Submission 83*, p. 31.

28 Victorian Advocacy League for Individuals with Disability Inc. (VALID), *Submission 149*, p. 7.

29 Ms Mary Mallett, CEO, DANA, *Committee Hansard*, Canberra, 21 August 2015, p. 10.

30 Ms Taryn Harvey, *Committee Hansard*, Perth, 10 April 2015, p. 38.

services being funded by the department upon whom the recipients of the service rely.³¹

7.36 The committee notes the Victorian Ombudsman's recommendation for an increase in funding for advocacy services informed by a comprehensive assessment of the advocacy needs of people with disability.³²

Independence

7.37 Submitters and witnesses emphasised that for advocacy services to be effective, they must be independent from the disability service organisations that may be perpetuating the abuse or neglect.³³ Mrs Silvana Gant from Adelaide People First told the committee:

...it is absolutely vital that people in institutional settings get access to real independent values driven advocacy support. That is not advocacy that is provided by the service; it is absolutely separate from it. It needs to be values driven. It needs to state very clearly what the advocacy stands for and believes in. It needs to have a sense of purpose and direction. There has to be a clear understanding of what advocacy is, because advocacy gets confused with service provision, support work, mediation and counselling.³⁴

7.38 Adelaide People First recommended that the following definition of independent advocacy be included in the Advocacy Framework:

To establish independence, an organisation or group needs to have advocacy as its core activity and not to be a provider of any services, especially the following: employment, accommodation support, personal care support, independent living support, respite, vocational training, brokerage, mediation, case management.

Advocacy for people with disabilities must be conducted by organisations or groups which are able to demonstrate independence from all actual, potential or perceived conflicting interests. Independence cannot be indicated by the separation of services from advocacy within an organisation or group.³⁵

7.39 Similarly, JFA Purple Orange, a social policy agency for people with disability in South Australia, highlighted the need for 'more proactive independent form of advocacy' particularly for people with intellectual disability.³⁶

31 Victorian Ombudsman, *Reporting and investigation of allegations of abuse*, p. 8.

32 Victorian Ombudsman, *Reporting and investigation of allegations of abuse*, p. 91.

33 See: Ms Mary Mallett, CEO, DANA, *Committee Hansard*, Canberra, 21 August 2015, pp 11–12.

34 Mrs Silvana Gant, President and Convenor, Adelaide People First, *Committee Hansard*, Adelaide, 28 August 2015, p. 10.

35 Adelaide People First, *Submission 116*, p. 17.

36 JFA Purple Orange, *Submission 12*, p. 24.

7.40 Evidence to the committee supported the findings of the Victorian Ombudsman's report into reporting and investigating allegations of abuse that found:

Advocacy services, and the funding of advocacy, should be independent of all agencies involved in funding, regulating, or providing services to ensure they can be truly fearless when standing up for the vulnerable.³⁷

Access to institutions and residential settings

7.41 Another significant challenge for advocacy services is having regular access to institutions and residential settings to assist people with disability in identifying and reporting abuse. JFA Purple Orange submitted that one of the main challenges of formal advocacy includes 'difficulties accessing service settings to observe what is occurring on a day to day basis'.³⁸ Similarly, Advocacy Tasmania noted that:

The benefits of advocacy within residential and institutional settings require advocates to have access to, and a presence within, these settings. This depends upon receiving sufficient funding to employ visible and effective advocates, who are able to act and respond promptly to abuse and neglect.³⁹

7.42 The committee heard that the structure of current reporting mechanisms that rely on individuals raising complaints present barriers to people with disability if they do not have access to advocacy services or other supports. Ms Taryn Harvey, CEO, Developmental Disability WA told the committee:

I think the current processes we have in place, where the onus is on the individual to raise complaints—and we also see where members of the workforce also want to raise issues of concern that they have—is that we do not have the kind of structures in place that can support people to make complaints successfully. When you have an individual who is feeling vulnerable and their family is feeling vulnerable, it is very difficult to raise a complaint of this significance within a service provider without support. If you are someone who does not have the kind of informal support...then that becomes more challenging again. Obviously there are the issues around how we are responding to those complaints from a justice point of view. We know that there are significant barriers to victims with disability of violence, abuse and neglect having recourse to the kinds of processes that the rest of us would take for granted.⁴⁰

37 Victorian Ombudsman, *Reporting and investigation of allegations of abuse*, p. 9.

38 JFA Purple Orange, *Submission 12*, p. 23.

39 Advocacy Tasmania Incorporated, *Submission 97*, p. 7.

40 Ms Taryn Harvey, CEO, Developmental Disability WA, *Committee Hansard*, Perth, 10 April 2015, p. 29.

Committee view

7.43 The committee recognises the crucial role that formal advocates play in assisting people with disability to identify and report violence, abuse and neglect.

7.44 The committee supports the view of many submitters that advocacy services must be independent of disability service providers and must have regular access to institutions and residential facilities.

7.45 The committee acknowledges that funding for formal advocacy services is provided at the state, territory and Commonwealth level and that these funding programs are currently under review.

7.46 However, the committee acknowledges that evidence from people with disability and advocacy service providers indicates that advocacy is underfunded and undervalued. The committee considers that advocacy services are vital to ensuring people with disability have access to supports to assist them to identify and report abuse.

Self-advocacy

7.47 The committee heard that self-advocacy is one of the most important forms of advocacy, whereby people with disability are provided with information about their rights and assisted to identify and report incidents of abuse and neglect.⁴¹ Ms Sonia di Mezza, Deputy CEO of the ACT Disability, Aged and Carer Advocacy Service told the committee that self-advocacy is 'just as important' as individual advocacy:

We find, with the spectrum of clients we have, that some people cannot communicate what they want and really need an advocate to help them. At the other end of the spectrum, other people are extremely articulate and we just stand next to them while they say what is wrong and what they want. There is a whole range. It is very important that we recognise that we need both self-advocacy and independent advocacy per se, and we need more funding for that. There is definitely not enough, I understand. There seems to be very much a push, in general, away from the word 'advocacy'. I am fearful that perhaps the support that is needed in this area is becoming more and more narrow. Both areas definitely need to be covered.⁴²

Role of self-advocacy

7.48 The committee heard that self-advocacy plays an important role in teaching people with disability about their rights. Ms Christina Ryan from Advocacy for Inclusion told the committee that in many cases, people with disability do not feel they have the same rights as everyone else:

41 See: National Disability Services, *Submission 111*, p. [7]; Working Alongside People with Intellectual and Learning Disabilities – Sexual Violence Prevention Association, *Submission 127*, p. [12]; Sally Bailey, *Submission 65*, p. 8; Action for More Independence in Disability Accommodation, *Submission 89*, p. 18; Leadership Plus, *Submission 95*, p. 2.

42 Ms Sonia di Mezza, *Committee Hansard*, Canberra, 21 August 2015, pp 35–36.

One of the most wrenching things for me—because we do the training for people in self-advocacy and human rights—is when people ask us: 'Do I have the same rights as other people?' They know they are cut off from the world and they know they are shut off. What they also know is that everybody else has rights and they do not. Every time we talk about delaying things, every time we do not respond, every time we do not have enough advocacy funding and every time the national plan to reduce violence against women does not actually do much for women with disabilities, we are reminding people with disabilities that we do not have the same rights. We do not matter. It is as simple as that.⁴³

7.49 Self-advocacy may also play an important role in assisting people with disability to identify abuse and inappropriate behaviour. Ms Michelle Moss, Project Manager from the Queenslanders with Disability Network told the committee:

I think there is some really important work that needs to be done about how we ensure that people with disabilities can understand that what is happening to them is not okay, and the support and education that needs to happen so that people do have a language and people do have a frame of reference, because historically we know that that has not been recognised and given to people. They do have the right to an education about sexual and intimate relationships.⁴⁴

7.50 In particular, witnesses highlighted the need for education for women and girls with disability about domestic or family violence. Ms Margie Charlesworth, Convenor of Women with Disabilities in South Australia told the committee:

It was somewhat startling to realise that there are many women with disabilities who do not always recognise or understand that they have been or continue to be victims of domestic violence and abuse. In the early stages of hosting these workshops, women were hesitant to attend them alone. They needed to bring someone with them who represented safety. I remember one young woman who did not contribute much. It was only when I read her feedback form that I realised how much these workshops meant to those who participated in them. Her comment was simply: 'I never knew that what I was experiencing was violence and that it was wrong.'⁴⁵

Availability of self-advocacy

7.51 Submitters and witnesses suggested that across jurisdictions, the availability of self-advocacy services is limited. Ms Aine Healy from the NSW Council for Disability told the committee:

The availability of self-advocacy for people is very limited. Victoria has some good networks and Tasmania has as well for people with intellectual disability. There are only one or two groups in New South Wales, so it is

43 Ms Christina Ryan, General Manager, Advocacy for Inclusion, *Committee Hansard*, Canberra, 21 August 2015, p. 10.

44 Ms Michelle Moss, *Committee Hansard*, Brisbane, 16 October 2015, p. 10.

45 Ms Margie Charlesworth, *Committee Hansard*, Adelaide, 28 August 2015, p. 13.

funded in a very ad hoc way across Australia. Again, that affects people's ability to speak up.⁴⁶

7.52 A survey conducted by DANA of disability advocates to provide to DSS on the proposed quality and safeguarding framework, indicated that many people with disability do not have access to self-advocacy training and programs:

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.⁴⁷

Government funded self-advocacy

7.53 A number of witnesses highlighted that the model of self-advocacy funding in Victoria provides a possible best practice model for other jurisdictions. In 2007, the Victorian Government funded the establishment of the Self Advocacy Resource Unit (SARU) (see Box 7.3).⁴⁸ Women With Disability Victoria submitted that the SARU model:

...has demonstrated the power of supporting self- advocacy. SARU support a range of groups which are run by, for example, people with Acquired Brain Injury, people with intellectual disabilities, and people with intellectual disabilities who have lost their children through child protection. Members of these groups work together, setting goals, running forums, sharing information, meeting with government representatives, and making change.⁴⁹

46 Ms Aine Healy, Executive Director, Advocacy, NSW Council for Intellectual Disability, *Committee Hansard*, Sydney, 27 August 2015, p. 5.

47 Ms Mary Mallett, CEO, DANA, *Committee Hansard*, Canberra, 21 August 2015, p. 9.

48 Department of Human Services, 'Disability advocacy organisations', <http://www.dhs.vic.gov.au/for-service-providers/disability/protecting-rights/disability-advocacy/disability-advocacy-organisations> (accessed 28 October 2015). A similar support network is provided in Tasmania through the Speak Out Association of Tasmania, an advocacy service and membership organisation for people with disability. See: Speak Out Advocacy, <http://www.speakoutadvocacy.org/> (accessed 29 October 2015).

49 Women with Disability Victoria, *Submission 53*, p. 41.

Box 7.3: Victoria - Self Advocacy Resource Unit

The SARU was established in 2007 and is funded by the Victorian Department of Human Services. The role of the SARU is to 'resource and support self advocacy groups run by and for people with intellectual disabilities', including people with high communication support needs.

In its submission to the review of the National Disability Advocacy Framework, the SARU noted that its key functions are to:

- strengthen and build the capacity of existing self-advocacy groups;
- support the establishment of new groups;
- promote Network Development;
- develop resources materials to support self-advocacy; and
- describe and improve advisor practice.

The submission suggested that the SARU model has 'proven highly successful in reinvigorating self-advocacy across Victoria' and increasing the number of self-advocacy groups, including two state-wide networks.

According to SARU, a 2012 evaluation of the model found it was 'a highly efficient and effective means of supporting groups to develop and grow'. The SARU also enables self-advocacy groups to be linked with local advocacy services.

Source: Self Advocacy Resource Unit, Submission to the Department of Social Services Review of the National Disability Advocacy Framework, July 2015, <https://engage.dss.gov.au/ndaf-2/public-submissions/> (accessed 28 October 2015).

7.54 Ms Mary Mallett told the committee that the SARU is one of the key reasons self-advocacy is more prominent in Victoria than other jurisdictions:

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.⁵⁰

Disability service provider funded self-advocacy

7.55 A number of disability service providers noted that they provide some form of self-advocacy training for people with disability.⁵¹ For example, Optia, a disability service provider in Tasmania, noted it works with a government funded self-advocacy organisation, Speak Out Advocacy, to deliver self-advocacy training:

Optia has partnered with Speak Out Advocacy to deliver a self-advocacy program, Road to Success, designed to increase confidence and self-determination of clients. The program includes a number of workshops run by an advocate and a peer (self-advocate) and covers topics including self-expression, self-confidence, self-determination, self-reliance, self-

50 Ms Mary Mallett, CEO, DANA, *Committee Hansard*, Canberra, 21 August 2015, p. 14.

51 See: Northcott, *Submission 58*, p. 2; Optia, *Submission 19*, p. 5; Endeavour Foundation, *Submission 27*, p. 8.

development and self-esteem. This program, piloted in 2013-14, is being expanded across the whole organisation this year (2015).⁵²

7.56 Similarly, the Endeavour Foundation, a disability service provider in Queensland, submitted that it has established a 'Community and Advocacy Support Unit' to support self-advocacy and leadership development. This includes a peer education service to provide information about the NDIS for people with intellectual disability, funded by the NDIS Practical Design Fund:

Self-empowerment and leadership development were integral parts of the program for the peer educators and the improved confidence of the individuals involved in the project was remarkable. The peer educator model used for this project has now been taken up by Queenslanders with Disability, a prominent network of people with a disability, who with initial support from the Community and Advocacy Support Unit and Queensland State Government funding, have continued to make these workshops available for Queenslanders with an intellectual disability.⁵³

7.57 In Victoria, Professor Jeffrey Chan told the committee that Yooralla has also implemented a self-advocacy program called the 'Life Skills Speaking Up' program:

The program, consistent with the latest literature, has four modules. It is about self-protected behaviours and understanding your rights and how to exercise your rights. It has a module on how to speak up if you feel that you can identify abuse. Fourthly, there is a module on how to make a complaint.

The program was delivered to more than 200 individuals with varying levels of cognitive impairment, including those who use the augmented communication device that you have referred to. One of the things that we have learned after delivering to more than 200 participants is that a group of them decided that they wanted to meet and to continue to meet and they formed their own self-advocacy group called the YES group—which is Your Enquiries Solved. That group is chaired by two people with intellectual disability, and my team supports them. They go out and meet on a regular basis. We intend to roll out that program consistently across the organisation.⁵⁴

7.58 However, some submitters raised concerns about self-advocacy programs run by disability service providers. Adelaide People First, an advocacy organisation in South Australia expressed particular concerns that these programs are:

...institutionalised, tokenistic "self advocacy" programmes or committees and/ or so call "independent advocates" where the service provider controls people's access to information, peer support and real independent, advocacy support.⁵⁵

52 Optia, *Submission 19*, p. 5.

53 Endeavour Foundation, *Submission 27*, p. 8.

54 Adjunct Professor Jeffrey Chan, Chief Practitioner, Yooralla, *Committee Hansard*, Melbourne, 30 June 2015, p. 7.

55 Adelaide People First, *Submission 116*, p. 12.

7.59 Adelaide People First evolved from Self Advocacy for Intellectually Disadvantaged People SA Inc. (SAID), a self-advocacy group established by a disability service provider in South Australia in the 1980s. Adelaide People First submitted that their past experience indicates that self-advocacy programs run by disability service providers 'fails to address the power imbalance between people with lived experience of intellectual disability and institutionalised disability service providers controlling our lives':⁵⁶

Our lived experience at SAID Inc., was one of being labelled, having low expectations and institutionalised thinking applied to us individually and collectively. We had our access to information controlled by the disability service providers and the Co-ordinator without disability within SAID Inc. We were segregated and isolated from people or organisations the disability service system and Co-ordinator without disability didn't want us having contact with and congregated or grouped together and treated all the same. This exposed us to abuse, discrimination, intimidation, victimisation, sexual harassment and exploitation.⁵⁷

Access to self-advocacy

7.60 Where self-advocacy programs are available, the committee heard particular concerns from advocacy organisations that people with disability are prevented from accessing their services, often by disability service providers. Ms Christina Ryan, General Manager of Advocacy for Inclusion told the committee:

People told us quite clearly that they are being prevented from participating in the activities that they choose to participate in. Somebody wants to participate; they want to come to a course that we are running or the self-advocacy group on a regular basis, and it is just made impossible for them to be there. Something always turns up, or they do not get their mail. A good half of people do not get their own mail despite the fact that providers will deny that until they are blue in the face—including government providers, which is very disappointing.⁵⁸

7.61 Ms Mallett suggested that disability service providers deliberately limit access to self-advocacy services:

Services who do not give the person the letter inviting them to the self-advocacy group meeting because they do not want to know that it is on. They make sure that the van is being used for something else that night so that they cannot get people to the meeting. There are many ways a service can do this.⁵⁹

56 Ms Silvana Gant, President and Convenor, Adelaide People First, *Committee Hansard*, Adelaide, 28 August 2015, p. 8.

57 Adelaide People First, *Submission 116*, p. 13.

58 Ms Christina Ryan, *Committee Hansard*, Canberra, 21 August 2015, p. 14.

59 Ms Mary Mallett, *Committee Hansard*, Canberra, 21 August 2015, p. 14.

7.62 Ms Ryan noted that by preventing people with disability accessing self-advocacy training, service providers and guardians are perpetuating a form of abuse:

There are some vicious perpetrators out there; let us acknowledge that. We know that. We have heard some appalling stories. But there are also people who are incredibly controlling and protective to the point of smothering people with the very, very best of intentions. What they are doing is perpetuating a form of abuse which would not be acceptable to any other member of the community. It is a very difficult space in that regard. We simply have to provide opportunities for people with disabilities to articulate independently. We often find this with advocacy, when we are able to sit down with a person. We are doing one-on-one training at the moment around self-advocacy and preplanning with people in group houses. About half the people we are currently working with are not allowed to just sit down with our training staff. They have to have their guardian or their support worker or their family member sit alongside them just to make sure.

Senator McLUCAS: Just to make sure of what?

Ms Ryan: Exactly! Good point. We know from working with people individually over the years through individual advocacy that they often say stuff to us that they would never say in another space if the person was present. It is a bit like teenagers talking when their parents are there. You are not going to say all these things. You need to be able to say something. You want to test drive it. Often it is because the person does not want to upset the people that care about them. They do not want to say, 'All of this hard work you've gone to to get me into this house that I hate living in; I would rather do something else. I do not want to be saying that. It's upsetting.' So they do not say it. But the reality is that they are forced into an environment they do not like.⁶⁰

Committee view

7.63 The committee recognises that self-advocacy services play a vital role in providing people with disability with support and training about how to identify and report abuse. In particular, self-advocacy services provide education about human rights and appropriate behaviour that are integral in assisting people with disability to understand what abuse is and how it can be stopped.

7.64 The committee acknowledges that the Victorian model for funding dedicated self-advocacy services provides a good example for other jurisdictions.

7.65 The committee is deeply concerned by evidence that suggests that the availability of self-advocacy services is limited across jurisdictions. The committee is particularly concerned by evidence that suggests people with disability are actively prevented from accessing self-advocacy services. The committee considers that all

60 Ms Christina Ryan, General Manager, Advocacy for Inclusion, *Committee Hansard*, Canberra, 21 August 2015, p. 13.

people with disability in institutions and residential settings should have access to independent self-advocacy training and services.

Informal Advocacy

7.66 'Informal advocacy' refers to individual advocacy for people with disability undertaken on a voluntary basis, usually undertaken by a family member or friend.⁶¹ Submitters and witnesses highlighted the important role informal advocates have in assisting people with disability to report incidents of abuse and neglect. JFA Purple Orange submitted that:

Many people living with disability only have people in their lives who are paid to be there; potentially it could be these people who are perpetrating the violence or abuse. Without an informal network of support around that person it is highly unlikely that their voice will be heard.⁶²

Formal recognition of informal advocacy

7.67 The committee heard strong support for increased recognition of the role of informal advocates in the decision-making process for people with disability. Ms Sue Ash AO, CEO of UnitingCare West noted that while formal advocates work within legally designated frameworks such as the guardianship system, there is no similar framework recognising and regulating informal advocates:

...the issue for many people is that the formal systems have safeguards and quality frameworks. What I think we need to advocate for and try to establish is that, alongside of that, we have a community education process where families and others learn about not just their rights but what it means to keep a safe environment, particularly for some of those groups of people who I think are emerging groups.⁶³

7.68 Evidence from family members and other informal advocates suggested that the lack of formal recognition of their role means they are powerless to challenge or influence decisions made by disability service providers. Ms Cheryl McDonnell detailed a range of ways in which her expertise in caring for her daughter was disregarded by the service organisation, and she was not able to provide care instructions:

Mother as advocate lauded for being such a good advocate for her daughter, then treated as if she is a trouble maker, stupid, or crazy. Written care plan provided by family was ignored by staff. One staff member refused to read it as it was not written by a nurse. The care plan was written by Terri's mother following [years] of

61 DSS, 'Research of the Models of Advocacy Funded under the National Disability Advocacy Program', <https://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/research-of-the-models-of-advocacy-funded-under-the-national-disability-advocacy-program> (accessed 30 October 2015).

62 JFA Purple Orange, *Submission 12*, p. 25.

63 Ms Sue Ash AO, *Committee Hansard*, Perth, 10 April 2015, p. 8.

consultations with educators, health and rehabilitation experts. Verbal instructions as given by Terri's mother were ignored.⁶⁴

7.69 Ms Julie Pianto, who alleged that her son experienced abuse in a supported residential facility managed by the EW Tipping Foundation in Victoria, told the committee that parents who advocate for their children are 'demonised' by disability organisations:

...one other insidious form of abuse inflicted by these organisations is that parents advocating for their loved ones are demonised, lied about and generally labelled as being difficult, argumentative or worse.⁶⁵

Informal advocacy in guardianship decisions

7.70 A key concern raised by multiple submitters, is how the lack of a legally recognised or defined role affects the capacity of informal advocates to participate meaningfully in the guardianship process. As discussed in Chapter 4, the committee heard concerns that legal guardians do not always act in the best interests of the person with disability when making decisions on their behalf. In some concerning cases, disability service providers may apply or threaten to apply for guardianship for clients due to disagreements with family members about care or treatment.

7.71 Evidence to the committee suggested that in Queensland, informal advocates, particularly family members, are often excluded from participating in the process to determine guardianship for people with disability. QAI submitted:

Bureaucratic processes...exclude informal advocates and family members from guardianship status (by which they can formally participate and have a voice in proceedings affecting a person with disability). In particular, in guardianship proceedings before the Queensland Civil and Administrative Tribunal, service providers are often successful in arguing for the formal removal of a person's familial or supportive network from the guardianship role.⁶⁶

7.72 The committee heard many examples of cases where informal advocates were excluded from the guardianship process. For example, Ms Sharon Richards, acting CEO of Advocare, a human rights and advocacy organisation in Western Australia, told the committee of one example where guardianship for a woman with cognitive impairment was transferred from her children to the service provider due to disagreements over medication:

...[she] liked to remove her clothes from her wardrobe, fold them and leave them on her bed. The facility responded to this by having locks put on the wardrobe. She became agitated, and her behaviour became more difficult to manage. The facility wanted to sedate her to reduce the agitation, but her family wanted them to investigate alternative methods. They were reluctant. When an accommodation or agreement could not be made, the institution

64 Ms Cheryl McDonnell, *Submission 37*, p.2.

65 Ms Julie Pianto, *Committee Hansard*, Canberra, 21 August 2015, p. 16.

66 QAI, *Submission 43*, p. 21

went to the state administrative tribunal, and the family were removed as guardians and a public guardian appointed. The woman now resides in a mental health facility. According to her family, her capacity to deal with anything is very reduced and she is being heavily medicated. At no time did the facility actually try any alternative methods to deal with this lady's behaviour.⁶⁷

7.73 Ms Richards further noted that in this case, the evidence provided to support the guardianship application on medical grounds was not provided by a medical practitioner, and yet the application was still supported:

We were all completely astonished that that guardianship was removed from the family because the family were incredibly supportive and really behind their mother and looking after her. For it to be turned over and the woman to be medicated—we were shocked. We believe that one of the things that actually happened—although we were not at the hearing, we had teleconferenced in—was that a person who was represented as an expert gave evidence that the lady had had a psychotic episode. In actual fact, it turned out the person who had said this was a cert III care worker off the floor. It was not a doctor, so the evidence or the information that was given really was not appropriate.⁶⁸

7.74 Witnesses suggested that there should be alternative options for families and disability service providers to deal with decision-making and disputes, rather than applying for formal guardianship. Professor Richard Bruggemann, the Disability Senior Practitioner in South Australia (appearing in a private capacity), told the committee:

I was always of the view that you do not go to the guardianship board if you can avoid it. When you have got a fight with mum and the organisation, fix the fight but do not go to the guardianship board. You will create enmity. I can remember one guy engineered to go away with his girlfriend on a trip and mum found out about it. He was going on trip to Cairns but he did not tell his mum that this young lady was going to Cairns. They did quite a good job of organising this. Then one of the staff members innocently said, 'I hope they have a nice time when they're away,' and mother exploded: 'This tart who wants his money!' and blah, blah, blah. One [of] my workers said, 'He's got a right to go. We should go to the guardianship board.' And his mum said, 'If he goes, he can live somewhere else.' We did not have anywhere else for him to live, and it was a good relationship. So you do not go to the guardianship board. You fix that up. You say to the mother, 'What are you scared about? How do we deal with that? How do we support you? What are the things he could do that you feel comfortable about? Okay, let's do that and see, when that works, what the next step is.' We often race to guardianship, when I think that there are other options. That is about the best advice I can give you. All I know is that it is difficult.⁶⁹

67 *Advocare, Committee Hansard*, 10 April 2015, p. 1.

68 *Advocare, Committee Hansard*, 10 April 2015, p. 5.

69 Professor Richard Bruggemann, *Committee Hansard*, Adelaide, 28 August 2015, p. 30.

7.75 In cases where guardianship is transferred away from family members, the committee heard that informal advocates have limited recourse to continue to advocate for the best interests of the person with disability. Where they attempt to do so, service providers may use the lack of formal legal authority to limit the informal advocate's access to the person with disability. Representatives from Speaking Up For You, an advocacy service in Queensland, told the committee:

Families reported that when they made a complaint to the service provider they were discredited and in some cases were denied access to the family member. In some cases the service provider made application to QCAT [Queensland Civil and Administrative Tribunal] and their family member was replaced by a public guardian. SUFY [Speaking Up For You] wrote to the director-general of Disability Services about the complaints and we did not receive a reply from him. We met with the public guardian about the complaints raised by the family. The public guardian was aware of the service; however, he said that he could not investigate the concerns we raised unless there was a person residing at the respite facility at the time of our complaint, and there was not.⁷⁰

7.76 Witnesses and submitters supported formal recognition of informal advocates in the guardianship process. QAI suggested:

QAI acknowledges the significant value of informal supports for a person with a disability and calls for informal supporters to be accorded greater respect and status, as well as formal recognition within bureaucratic guardianship processes.⁷¹

7.77 However, evidence to the committee also emphasised that the views of informal advocates should only be recognised where they are acting in the interests of the person with disability. For example, Professor Richard Bruggemann told the committee of one example where a person with disability was denied medical treatment by his family:

Are parents the ideal guardians? In many instances. Usually. But there was a guy who lived at Strathmont Centre. He had testicular cancer; aged 42; highly treatable; nine out of 10 people survive. We took him to the doctor. The doctor suggested a course of treatment. We went to the family and said, 'Here is what the doctor would like to do'. And the family said, 'No, he has had a good run. Let him die'. And we went to the guardianship board, and miscued—because what we should have gone there for was not to have the treatment approved but to change the guardian. We went to the district court to appeal it, and they appointed the public advocate as the guardian. He then approved the course of treatment. We wrecked our relationship with the family. They would not speak to us. There was almost a fight on the lift. And then the guy died. He was one of the one in 10.⁷²

70 Ms Dianne Toohey, Coordinator, Speaking Up For You Inc., *Committee Hansard*, Brisbane, 16 October 2015, pp 34–35.

71 QAI, *Submission 43*, p. [21].

72 Professor Richard Bruggemann, *Committee Hansard*, Adelaide, 28 August 2015, p. 30.

7.78 Similarly, the Tasmanian Government noted examples where guardianship was transferred from families to ensure the wishes of the person with disability may be met:

A 93 year old man with dementia was deprived of contact with his female companion of many years when an aged care facility acted on instructions from the man's family who did not approve of the friendship (but contrary to the resident's wishes). When a guardian was appointed and contact was resumed, the pair had been separated for 12 months.⁷³

Guardianship: transitioning to adulthood

7.79 The committee heard concerns about the role of families in the decision-making process for people with disability under guardianship orders once they turn 18 years old. Ms Mary-Lou Carter of Our Voice Australia described the situation that many parents faced:

When our children turn 18, we as their parents have absolutely no authority whatsoever-no legal standing. I was told that in no uncertain terms in black and white by Robert McClelland when he was the Attorney-General back in 2008. I wrote to him specifically with that question. 'Do I have any legal authority?' He told me no. It makes families so anxious, particularly as their children approach that magical majority.⁷⁴

7.80 Submitters and witnesses expressed concern that to retain the legal capacity to seek information and direct care for children with disability, families have to apply through a tribunal or court for guardianship of their children once they turn 18 years old. Witnesses from Our Voice Australia told the committee:

There has to be an easier way than going to the guardianship tribunal and having complete strangers judge us on whether we are capable and looking to the best interest of our children. It is just appalling to be in that situation.⁷⁵

7.81 The NSW Public Guardian told the committee that some jurisdictions have considered options for streamlining the guardianship process when a child with disability turns 18, but the issue remains unresolved:

Attorneys-general across Australia have been in receipt of representations from various groups suggesting that, when a person reaches the age of 16 or 18, where their family have been their key source of support historically, there would be some sort of automatic or streamlined conversion of the parental responsibility into guardianship. I know for example that the

73 Tasmanian Government, *Submission 74*, p. 24.

74 Ms Mary-Lou Carter, Secretary, Our Voice Australia, *Committee in-camera Hansard*, Sydney, 27 August 2015, p. 4.

75 Our Voice Australia, *Committee in-camera Hansard*, 27 August 2015, p. 4.

Victorian parliament considered that issue. But to my knowledge none of the parliaments in any of the jurisdictions has actually agreed.⁷⁶

Aboriginal and Torres Strait Islander people with disability

7.82 As discussed in Chapter 4, The North Australian Aboriginal Justice Agency (NAAJA) highlighted that in the Northern Territory, Aboriginal and Torres Strait Islander peoples are significantly overrepresented in the number of people on adult guardianship orders, with 50 per cent of people subject to guardianship orders identifying as Aboriginal.⁷⁷ NAAJA noted that the number of people under guardianship in the NT is eight times more than the next highest jurisdiction (NSW).⁷⁸

7.83 NAAJA expressed concern that:

Intellectually disabled Aboriginal people in remote communities are particularly vulnerable to abuse and neglect because of a lack of services and support. There is a critical lack of disability services for Aboriginal people in remote communities and a lack of support and education for families and community members to assist them to care for disabled family members.⁷⁹

7.84 NAAJA provided the committee with case study examples that highlight that Aboriginal people under guardianship orders are not adequately protected and require specialist advocacy support (see Box 7.4).

76 Mr Graeme Smith, Public Guardian, NSW Office of the Public Guardian, *Committee Hansard*, 27 August 2015, p. 23.

77 NAAJA, *Submission 138*, p. 4.

78 *Submission 138*, p. 9.

79 *Submission 138*, p. 9.

Box 7.4: Case study – adult guardianship for Aboriginal and Torres Strait Islander people

Ms M has an intellectual disability, multiple medical conditions and comes from a remote community. Following a recent medical procedure, she is required to take medication once a day for the rest of her life. She cannot return to her home community because she does not have the capacity to monitor her own medication intake and the clinic there does not have the resources to provide this service. She has no family and nowhere to live outside her community and has to stay in hospitals as there is no suitable supported accommodation.

NAAJA noted that Ms M did not have capacity to give consent to the procedure and was not provided a support person or interpreter. The Office of the Public Guardian (OPG) has been appointed her guardian to make decisions about where she lives and her day to day medical care. However, NAAJA noted that OPG 'does not have the resources to act as an advocate' and was unable to assist Ms M during a recent medical procedure:

...on her own in the hospital, without an advocate or caseworker, she was neglected and vulnerable. At one point when she left the hospital to be with her partner it was assumed she was out drinking (she does not drink) and this led to a misunderstanding that she was refusing treatment and 'non compliant'. At another point she was almost discharged back to a smaller hospital without having the operation required. Ms M has had this operation but is still in hospital waiting for a placement in supported accommodation.

Ms N was the subject of a report by the NT Health and Community Services Complaints Commissioner in February 2014. NAAJA noted that the Public Guardian and two family members had been appointed as Ms N's guardian and there had been 'clear and consistent warnings about the neglect, physical and sexual abuse and ongoing suffering of Ms N that various government agencies had not acted upon'.

The Commissioner found that the Public Guardian, the Department of Health and other health service providers (such as the local clinic) were aware that Ms N was vulnerable and unable to care for herself. It was also evident that her family was not coping with her high care needs and was not getting the support they needed. The Commissioner found that all services involved in Ms N's care and daily life 'failed to protect her, to ensure her safety, and to promote her wellbeing, her dignity and her place in the community'.

Source: NAAJA, Submission 138, p. 10–12.

7.85 Ms Pip Martin, Managing Solicitor from NAAJA, told the committee of the importance of advocacy services for people under guardianship orders:

...the lack of coordinated service provision for people who have intellectual disability means that we see people who are falling through the cracks. People who are even under the management of the Public Guardian are not individually case managed, so certain problems arise. We would recommend individual disability advocates to case manage people who are under the Public Guardian.⁸⁰

7.86 NAAJA expressed concern that in the Northern Territory:

80 Ms Philippa Martin, Managing Solicitor, Civil Law Section, NAAJA, *Committee Hansard*, Brisbane, 16 October 2015, p. 21.

...even when the Public Guardian is appointed there is no guarantee that a person is protected from financial or physical abuse. There is a clear need for an independent disability advocate for each person under guardianship and without such an advocate, there is a risk of that person suffering neglect and abuse.⁸¹

Committee view

7.87 The committee affirms the view that the focus for all policy and practice must be centred on the person with a disability. The committee also recognises the vital role played by informal advocates, including families, in safeguarding people with disability against violence abuse and neglect.

7.88 Evidence to the committee highlighted concerns that informal advocates are not recognised under most existing legal frameworks, particularly in relation to guardianship decisions. Further evidence to the committee suggests the views of informal advocates are often overridden by those of disability service providers.

7.89 The committee recognises the need for greater legal recognition of the important role informal advocates can perform in the decision-making process for people with disability. The committee considers that there should be mechanisms in place to allow informal advocates to assist people with disability, particularly those with intellectual disability and cognitive impairment, to raise allegations of violence, abuse and neglect.

7.90 As discussed in Chapter 4, the committee is deeply concerned by evidence that suggests that disability service providers may use guardianship orders to circumvent the advice of informal advocates. The committee does not think it appropriate that service delivery organisations can also hold the threat of guardianship orders over their clients.

7.91 The committee emphasises its support for the establishment of a supported decision-making model for people with disability that recognises the role of informal advocates. The committee considers this model is integral to safeguarding people with disability against violence, abuse and neglect.

7.92 The committee also recognises that informal advocates are not recognised in the decision-making process for adults with disability. The committee supports streamlining this process to enable family members to have a recognised role in decision-making, without having to apply for formal guardianship, consistent with a supported decision-making model.

7.93 The committee is particularly concerned by evidence that Aboriginal and Torres Strait Islander peoples are over-represented in the adult guardian system, which leads to them not getting individualised support. The committee considers that special consideration must be given to how to provide individual case management support for Aboriginal and Torres Strait Islander people with disability.

81 NAAJA, *Submission 138*, p. 11.

Advocacy under the NDIS

7.94 The committee heard strong support for increased funding for all models of advocacy during and after the transition to the NDIS. Advocacy for Inclusion submitted that:

People with disabilities need long-term support to build self-advocacy skills, and they also need independent individual advocacy support in the highly likely instance that regardless of their self-advocacy skills, other people continue to exert power over the person's life.⁸²

7.95 Specific advocacy support for engaging with the NDIS on individual support packages is discussed in detail in Chapter 9.

Advocacy funding

7.96 In February 2015, the Australian Government, together with states and territories, launched a consultation process for the Information, Linkages and Capacity Building (ILC) policy for the NDIS (formerly known as 'tier 2'). The ILC is:

...a key component of the NDIS insurance model and will contribute to the sustainability of the NDIS by building the capacity of the community, people with disability, their families and carers which in turn will reduce the need for funding of supports for people with disability through Individual Funded Packages.⁸³

7.97 In April 2015, the Council of Australian Governments' Disability Reform Council considered the findings of the consultation process and agreed that in relation to advocacy, the NDIS would fund:

- decision supports;
- safeguard supports; and
- capacity-building for participants, including support to approach and interact with disability supports and access mainstream services.⁸⁴

7.98 The Disability Reform Council agreed that systemic advocacy and legal review and representation would be funded outside the NDIS. DSS noted that this is consistent with the 2011 PC Inquiry Report into *Disability Care and Support*, which recommended that advocacy be funded and provided outside the NDIS:

Systemic advocacy pushes for broad policy and social change, while individual advocacy promotes the interests of particular individuals by acting on their behalf to resolve specific issues. These functions should lie

82 Advocacy for Inclusion, *Submission 83*, p. 33.

83 National Disability Insurance Scheme (NDIS), *Draft Framework for Information, Linkages and Capacity Building*, Consultation on Information, Linkages and Capacity Building, <http://www.ndis.gov.au/consult-info-link-capacity-building> (accessed 23 October 2015).

84 See: Council of Australian Governments, Disability Reform Council, *Communiqué 24 April 2015*, <https://www.dss.gov.au/our-responsibilities/disability-and-carers/programmes-services/government-international/disability-reform-council> (accessed 22 October 2015).

outside the NDIS, reflecting the potential conflict of interest that would arise were the NDIS to fund advocacy bodies whose role was to challenge the disability system overseen by the NDIS.⁸⁵

7.99 The resultant ILC Framework published in August 2015, acknowledges that the NDIS 'has an important role to play in providing decision-making supports and building individual capacity for people to advocate for themselves (self-advocacy)'.⁸⁶

7.100 DSS submitted that the Commonwealth government together with states and territories is 'working through the elements of advocacy that will be funded by the NDIS and how it will align with services delivered under NDAP [Advocacy Program]'.⁸⁷

Transition to NDIS

7.101 A number of submitters and witnesses highlighted that funding for advocacy services was not included in the draft NDIS Quality and Safeguarding Framework discussion paper.⁸⁸ These submitters and witnesses strongly recommended that advocacy be considered central to the safeguarding framework for the NDIS. Ms Colleen Pearce, the Victorian Public Advocate, told the committee that funding for advocacy should be central to the NDIS safeguarding framework:

My recommendation is for the Commonwealth government to commit to funding an advocacy program as a crucial NDIS safeguard. Such programs and funding should remain separate from any of the funding provided to the NDIS participants.⁸⁹

7.102 Ms Aine Healy noted that the NSW Council for Disability's recent consultations for DSS on the proposed quality and safeguarding framework found that:

...people said that having the opportunity to come together and talk about what is available and what is not and about practising your skills, being able to speak up, learning from other people et cetera would be really, really useful—having resources to do that stuff. But it is not available in an ongoing fashion. People said they would like to be able to build a relationship with a trusted organisation in one regional area. People told us: 'I like that I can drop in and out of that advocacy service. I haven't needed to use them for a few years, but when something comes up I know I can go in there, and I know I can do that.' Definitely some sort of block funding

85 See: PC, *Disability Care and Support*, Inquiry Report no. 54, vol. 1, 10 August 2011, p. 26, <http://www.pc.gov.au/inquiries/completed/disability-support> (accessed 22 October 2015).

86 NDIS, *A Framework for Information, Linkages and Capacity Building*, Information, Linkages and Capacity Building, <http://www.ndis.gov.au/ilc-policy> (accessed 22 October 2015).

87 The Department has not indicated a timeframe for this work to be completed. *Submission 104*, p. 27.

88 See: NDIS Quality and Safeguarding Framework, <https://engage.dss.gov.au/ndis-qsf/> (accessed 2 November 2015).

89 Ms Colleen Pearce, *Committee Hansard*, Melbourne, 30 June 2015, p. 33.

would be useful so that people can provide a basis for systemic work and for individual work as needed, because you are not always going to be able to pick when you might need individual advocacy.⁹⁰

7.103 The committee notes many of the submissions to the NDIS Quality and Safeguarding Framework highlighted the absence of independent advocacy services. For example, Women with Disability Australia and People With Disability Australia's submission to the framework noted:

The proposed framework does not focus on the critical role of DPOs [Disabled Peoples Organisations], independent advocacy or disability support organisations (DSOs) in ensuring quality and safeguarding for people with disability. Yet, NDIS participants as well as those who are not NDIS eligible will need increasing support to navigate and adapt to the new service environment; government will still need consultation mechanisms to develop and implement effective policy; and independent voices will be needed to ensure that the market for disability supports grows in a way which promotes human rights.⁹¹

7.104 Women with Disability Australia and People with Disability Australia recommended that:

DPOs, independent advocacy and DSOs should continue to be block funded and receive increased recognition that they remain fundamental to quality and safeguarding for people with disability.⁹²

7.105 Evidence to the committee supported the findings of the Victorian Ombudsman's report that 'the role of advocacy will need to be strengthened further with the introduction of the NDIS'. The Victorian Ombudsman noted:

It is not viable for advocacy to take a secondary position in the safeguards framework. I consider advocacy to be key in a framework for Victorian people with disability who have no prospect of becoming empowered consumers and have no family or friends to voice their best interests.⁹³

7.106 Some submitters recommended the introduction of an advocacy program independent of the NDIS, to ensure that advocacy services are adequately funded. For example, VALID in Victoria recommended an independent program to fund systemic and individual advocacy:

VALID believes there is a need for a strong and robust independent advocacy program that provides various forms of advocacy including

90 Ms Aine Healy, Executive Director, Advocacy, NSW Council for Intellectual Disability, *Committee Hansard*, Sydney, 27 August 2015, p. 5.

91 Women with Disabilities Australia and People with Disability Australia, *Submission to NDIS Quality and Safeguarding Framework*, p. 15, <https://engage.dss.gov.au/ndis-qsf-submissions/1435277763/> (accessed 2 November 2015).

92 Women with Disabilities Australia and People with Disability Australia, *Submission to NDIS Quality and Safeguarding Framework*, p. 18, <https://engage.dss.gov.au/ndis-qsf-submissions/1435277763/> (accessed 2 November 2015).

93 Victorian Ombudsman, *Reporting and investigation of allegations of abuse*, pp 89–88.

responsive as well as proactive strategies for identifying and addressing systemic abuse and neglect. Funding is also needed for individual and systemic forms of advocacy. This program needs to be funded to match demand from both a population growth perspective and a program demand perspective as the NDIS expands supports to a larger number of people with disabilities. Severe underfunding of independent advocacy can lead to cases of abuse and neglect going unaddressed as advocacy organisations build waiting lists for support. I think even in the transfer of some of the state advocacy funding to the NDIA there is a risk of losing some of the advocacy funding that is already in the system.⁹⁴

7.107 Submitters also highlighted the need to ensure self-advocacy services are adequately funded under the NDIS.⁹⁵

Concluding Committee view

7.108 The committee recognises the significance of formal advocacy, self-advocacy and informal advocacy services in assisting people with disability to identify and report violence, abuse and neglect.

7.109 Evidence to the committee suggests that there is a strong support for increased funding for formal advocacy services and self-advocacy training, and greater recognition of the important role played by informal advocates particularly under the NDIS.

7.110 The committee recognises the need for continued funding for all forms of advocacy during and after the transition to the NDIS. The committee supports the recommendation of the Victorian Ombudsman that funding for advocacy services should be increased, based on a fulsome assessment of the need across jurisdictions. The committee considers that this recommendation should be central to the Australian Government's current review of the Advocacy Program.

7.111 The committee considers that advocacy must be central to the quality and safeguarding framework for the NDIS. The committee considers that an independent advocacy program that funds all forms of advocacy services, such as the Advocacy Program, should continue under the NDIS.

7.112 While acknowledging the Australian Government is reviewing all aspects of advocacy funding, including the Advocacy Framework and the Advocacy Program, the committee is concerned by the current lack of detail on which advocacy services will be funded under the NDIS. In particular, it is not clear how systemic advocacy, which falls outside the NDIS framework, will be funded.

94 Mr David Craig, Project Coordinator, VALID, *Committee Hansard*, Melbourne, 30 June 2015, p. 44.

95 See: NSW Council for Intellectual Disability, *Submission 103 Attachment 1*, p. 14.

