Submission:

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability



Peak body for independent disability advocacy in Victoria

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- Southern Disability Advocacy
- United Brains self-advocacy network of ABI groups
- Women with Disabilities Victoria
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A. Executive Summary and Recommendations

- This submission assumes an acceptance by the Disability Royal Commission that the mistreatment of people with disabilities in Australia is prolific and requires urgent attention.
- 2. The financial cost of violence and abuse is very high, and often long term in relation to addressing trauma and health care needs. The human cost is even higher. These impacts are not restricted to people with disabilities, but also impacts their families and others.
- 3. Violence and abuse are present in many forms. For example, it was reported that NDIS providers used unauthorised restraints on clients more than 1 million times in 2020-2021¹. The removal of children from parents with intellectual disabilities on the basis of medical model assessments continues, often with lifelong consequences. Any deliberate withholding of education from children with disabilities would constitute inhumane treatment.
- **4.** Achieving inclusion for people with disability, a key requirement to reduce risk, relies not simply upon disability policy and practice. People with disability are fully-fledged citizens of our country, and as such, all relevant international agreements and covenants should clearly be referenced as a priority in policies, procedures and decision-making.
- 5. Currently, people with disability and those from systemic advocacy organisations are not genuinely involved in policy discussions across government departments. We claim "not genuinely", as, despite numerous working groups and reference committees at many levels of government, such consultation has not achieved inclusion for people with disabilities, or stopped violence and abuse against them.
- **6.** Given the decades that have seen little positive change in violence and abuse against people with disabilities, Disability Advocacy Victoria views the Royal Commission as the only real opportunity to change the status quo for people with disability.
- 7. The key findings and recommendations in this submission respond to the Terms of Reference and specific questions² outlined in the DRC's Letters Patent³.
- **8.** For the purposes of this submission, we refer to violence, abuse, neglect and exploitation as "violence and abuse".

¹Henriques-Gomes, L. (2021, November 10) 'NDIS providers used unauthorised restraints on clients over a million times in 12 months' *The Guardian: Australia Edition https://www.theguardian.com/australia-news/2021/nov/10/ndis-providers-used-unauthorised-restraints-on-clients-over-a-million-times-in-12-months*

² Refer to heading B3.

³ Commonwealth of Australia, 2019, Commonwealth Letters Patent https://disability.royalcommission.gov.au/publications/commonwealth-letters-patent

A.1 Key Findings

- **9.** Disability Advocacy Victoria Inc ("DAV") found in relation to the barriers to **reporting** of violence and abuse:
 - a) The system has created circumstances and barriers that prevent people from speaking up for themselves and therefore launch a complaint about violence and abuse. These are likely to be the most vulnerable people who need assistance to communicate, those with complex and high support needs, people from CALD or First Peoples backgrounds, and some of those with ABI or psychosocial disability.
 - b) Some people do not report violence and abuse or complain even if they are able to do so, because they do not trust services, or they fear increased violence and abuse from a perpetrator, reprisals from staff, or losing services which makes them more vulnerable.
 - c) Many people with disability who spoke out were ignored, not believed, or seen as unreliable witnesses.
 - d) Supported Decision Making is underutilised, affecting the ability to report.
 - e) The likelihood of people with disability making and pursuing a complaint was far lower for people who were isolated and had few contacts, and for those who had no resources and support to change their circumstances.
 - f) Some people with disability who communicated their protest against the violence and abuse they suffered were seen as showing behaviours of concern, and restrictive interventions were then used to prevent their protest.
 - g) Service providers had vague and varied criteria as to what level of violence and abuse met the threshold for a formal complaint.
 - h) Isolation and segregation contributed to violence and abuse, and a reluctance/inability to report.
 - i) Many cases of violence and abuse are never recognised or seen.
- **10.** DAV found that in relation to **investigating** violence and abuse, this was hindered due to the following.
 - a) Many services have entrenched practices that involve the use of microaggressions (being indirect or subtle oppressions/discrimination), informal restrictions or a failure to educate their staff about human rights. This can result in neglect and exploitation of people not being recognised by staff. Practices that are not accepted or understood as constituting violence and abuse are unlikely to be reported or investigated.
 - b) Services often have a conflict of interest. We found services using internal inquiries instead of pursuing a formal complaint; having the power to deny that violence and abuse had occurred; and limiting access to family or disability advocates. This self-regulation is not working to prevent violence and abuse, as people with disability do not have an equal voice or authority in complaints and other formal procedures.
 - c) Service quality criteria as they exist at present, do not work sufficiently well-given violence and abuse can co-exist with high scores on service quality.
 - d) There are many systems at the state and federal levels that ostensibly address complaints. There is no one independent national complaints body that manages a complaint against all/any service providers (not just against NDIS

- service providers), with benchmarks for action/timing by involved parties. The complex communications, form-filling, as well as the adversarial nature of the process, disempowers people with a disability unless they have an advocate supporting them. Such disempowerment can result in withdrawal.
- e) The length and complexity of the formal complaints process were a barrier. Many people with disability do not have a place of safety available to them. The inappropriateness of a person who has made a complaint about a service provider needing to remain with that provider while the complaint is being investigated, is self-evident.
- f) There are insufficient services to support people practically and emotionally while going through the complaints process.

11. In relation to effective **responses** and preventative measures, DAV found that:

- a) The applicable laws, policies and regulations in place do not address the above issues sufficiently and provide generally inadequate protection.
- b) Public attitudes, government neglect and discriminatory attitudes toward service workers underpin many of the problems identified in our submission.
- c) The demand for advocacy is outstripping the capacity of the sector to respond. As cases become more complex, disability advocacy organisations are having to limit access to their services, and this will have an impact on their capacity to assist those reporting violence and abuse.
- d) Many people fell through the safety net after making a complaint. There are insufficient choices available for people in housing and services. Therefore, choice and control are illusory in many cases. It is unclear whose responsibility it is to ensure the safety, and sometimes removal, of a person who makes a complaint, and who is still under the power of those they are complaining about. Moreover, because housing, education and employment are areas of positive rights subject to progressive realisation under the UN Convention on the Rights of Persons with Disabilities ("CRPD"), this situation is unlikely to change quickly.
- e) There were systems issues: lack of availability of supported decision-making; service gaps for young people between 16 to 18 year old; unequal access to the law, and barriers to using disability discrimination laws to pursue a case.

12. The above barriers:

- a) mean that the known and reported cases of violence and abuse represent a small proportion of cases that occur;
- b) indicate when taken as a whole, institutionalised discrimination exists against people with disabilities;
- c) indicate that violence and abuse against people with disabilities have not been addressed.

A.2 Recommendations

Recommendation 1

The Commonwealth Government should adopt the Victorian preventative and proactive service model and adequately fund programs like the Community Visitors program and Independent Third Persons, embedded in the Office of Public advocate (OPA). These

programs can support and assist people with disability and monitor and report the adequacy of services provided to them in their home or work environment, providing a crucial safeguard for the protection and promotion of the human rights of people with disability.

Recommendation 2

In accordance with Australia's obligations under s42 of the United Nations Convention on the Rights of Persons with Disabilities, and in compliance with Article 21, enact a Commonwealth Communication Bill of Rights which enshrines the rights of people with disabilities to be taught how to functionally communicate at a minimum, and to fluently communicate where possible, through the method of their choice. The Bill of Rights would require all disability service providers, including schools, to commit to providing accredited Auslan Interpreters; accredited Deaf/Blind Interpreters; the provision of evidence-based literacy programs for those with language/learning disorders; and for people with little or no speech - Communication Partners, the provision of devices, accredited trainers, and the facilitation of the use of devices in all settings, at all times.

Recommendation 3

In accordance with Australia's obligations under s42 of the United Nations Convention on the Rights of Persons with Disabilities, and in compliance with Article 24 (General Comment 4), all Australian states to develop a 10-year plan to end segregated education. The exception to this is schools for the deaf, where such schools provide language access and same language peers. In such circumstances the Deaf community should be seen as a culturally and linguistically unique community rather than as simply a part of the disability community.

Recommendation 4

In accordance with Australia's obligations under s42 of the United Nations Convention on the Rights of Persons with Disabilities, and in compliance with Article 27, all Australian states to develop a 10-year plan to end segregated employment facilities, ensuring such facilities are replaced with further supported employment training programs.

Recommendation 5

In accordance with Australia's obligations under s42 of the United Nations Convention on the Rights of Persons with Disabilities, and in compliance with Article 19, all Australian states to develop a 10-year plan to end segregated housing we recognise the right of people with disabilities to live with each other of their own free will. (We refer to and repeat our comments in Recommendation 3 referring to the Deaf community as an exception),

Recommendation 6

That the Commonwealth protect the titles of "Board Certified Behaviour Analyst" and "Behaviour Analyst" to ensure that underqualified/unqualified persons cannot use these titles, misleading people with disabilities as to their training/certification. The Commonwealth to liaise with the Association for Behaviour Analysis Australia to further protect the community from unqualified persons claiming they can effectively mitigate the behaviours of concern.

Recommendation 7

Given the increased use of violence against people with disabilities by service providers through "restrictive practices", the regulation of "behaviour practitioners" be taken away from the NDIS Quality and Safeguards Commission and given to the Association for Behaviour Analysis Australia.

Recommendation 8

Given the unrealistic nature of the complete elimination of restrictive practices, restrictive practices in all settings to be prohibited unless specific interventions by qualified persons applying the scientific discipline of applied behaviour analysis have and are being applied by persons qualified in that field⁴, and certain environmental conditions are being met.

Given the number of unauthorised restraints, significant fines are immediately put in place against service providers in response to unauthorised restraint, except in extreme emergencies (for example in response to behaviours that are completely unexpected and have previously not been seen).

Recommendation 9

Ensure that disability service providers cannot receive registration through the NDIS unless they provide human rights training to staff annually, through a neutral training body, to ensure they have a contemporary understanding of practices and procedures in place to safely report instances of violations, and violence and abuse.

Recommendation 10

The model of the Victorian Disability Worker Commission is adopted nationally, with the exception that registration is mandated rather than optional, to enable a central register for workers from different disciplines who support people with disabilities of all ages as this would help minimise the risk of harm and neglect to people with disability by ensuring access to safe and quality services, and skilled and professional disability workers.

Recommendation 11

DAV endorses the recommendation of the Disability Discrimination Legal Service's submission⁵ to the Disability Royal Commission regarding introducing a centralised single regulatory agency that takes on the roles of the current diverse range of regulators that deal with disability (Quality and Safeguards Commission, Disability Workers Commission (Victoria), Ombudsman, Disability Services Commissioner). Meanwhile, greater emphasis needs to be placed on proactive monitoring of provider performance by the NDIS Quality and Safeguards Commission and appropriate processes must be in place to identify and address concerns and recurring complaints around particular services, as currently the Commission does not make full use of the extent of their reach and monitoring and enforcement powers (particularly in compliance with section 29 of the National Disability Insurance Scheme (Incident Management and Reportable Incidents) Rules 2018).

⁴ Association of Professional Behavior Analysts (2009) 'The use of Restraint and Seclusion as Interventions for Dangerous and Destructive Behaviors https://cdn.ymaws.com/www.apbahome.net/resource/collection/1FDDBDD2-5CAF-4B2A-AB3F-DAE5E72111BF/Restraint Seclusion .pdf

⁵ Disability Discrimination Legal Service (2021, 23 November) 'Disability Royal Commission Submission on Regulatory Bodies', paragraphs 117-119.

Recommendation 12

In accordance with Australia's obligations under s42 of the United Nations Convention on the Rights of Persons with Disabilities, and in compliance with Article 23, the Commonwealth ensure that:

- a) adequate funding is provided for parenting programs for persons with disabilities to allow any relevant person to take part in such program within one month of application;
- b) parenting programs are to be delivered in the language and modality most appropriate for the person with disability; and
- c) such programs are provided before any child can be removed from his/her parents unless that child is in extreme danger.
- d) State child protection/family government services are required to adopt policies regarding respect for home and family, commensurate with Article 23.

Recommendation 13

The Commonwealth Government should adequately fund social housing and bespoke emergency housing for people with disabilities in order that they have access to alternative accommodation if they wish to immediately escape violence and abuse in their home. DAV's preference would be that any new regulator ensures that workers accused of violence and abuse be immediately removed from the setting until an investigation is finalised.

Recommendation 14

Provide additional funding to advocacy services, funded by NDAP and other State and Territory government programs, to allow them to:

- a) assist people with disabilities to access all necessary systems (e.g., housing, family violence, community health, education, justice) and supports to prevent violence and abuse;
- b) provide support at the time of request (as currently the waitlists, closing of books etc cause delays in services responding to the clients in need);
- c) efficiently adapt following the revolution in delivery of disability support services across the nation since the introduction of the NDIS;
- d) effectively implement the legislative changes now in place that address the right to decision making;
- e) increase workforce capacity to meet unmet demand;
- better address complex needs, through working across multiple service systems such as NDIS, health sector, housing sector, family violence sector, and justice;
- g) reach people who are not able to access advocacy due to various challenges including significant disability, isolation, communication needs and closed service settings amongst others.

It is important that the Commonwealth Government ensures that:

- a) CPI indexed consistent funding is provided to support advocacy service continuity and sustainability; and
- ongoing and long-term funding grants are provided to enable forward planning, development and outreach (as outreach and preventative work is currently almost non-existent in the disability advocacy sector), and to retain skilled staff in the sector.

Recommendation 15

More funding is provided to disability self-advocacy groups given their effectiveness in building social and support networks to address isolation, training in assertiveness, human rights and advocacy.

B. About Disability Advocacy Victoria (DAV) Inc.

- **13.** Disability Advocacy Victoria Inc. (DAV) formerly known as Victorian Disability Advocacy Network (VDAN) was established in 2003. DAV is the peak body for independent disability advocacy agencies in Victoria.
- **14.** We strive to break down the walls for people with disability by working with key stakeholders to achieve positive, systemic change in the disability sector. With one united voice, we have a much greater influence on policymakers about issues that affect people with disability.

B.1 DAV aims

- **15.** DAV aims to:
 - a) strengthen the disability advocacy movement in Victoria;
 - b) promote rights-based advocacy;
 - c) raise awareness about the needs and rights of people with disability.

B.2 DAV: Guiding principles and values

- **16.** DAV is committed to operating in accordance with the following principles and values:
 - a) control by people with disabilities is central to the success of the advocacy sector;
 - b) diversity of approaches to advocacy is necessary to promote, protect and ensure⁶ the rights of people with disabilities;
 - c) responding to the diversity of needs, interests and aspirations of people with disabilities is a fundamental component of providing effective advocacy;
 - d) respect for the autonomy of individual member organisations;
 - e) DAV is most effective when all members are united;
 - f) member organisations have valuable experience and knowledge of the needs and rights of people with disabilities;
 - g) the role of advocacy is to promote and protect the rights and interests of people with disabilities and not those of other parties;
 - h) identifying and minimising conflict of interest is fundamental to the successful provision of advocacy services;
 - i) DAV members must endorse the rights of people with disability as set out in the UN Convention on the Rights of Persons with Disabilities ("CPRD").

⁶ The UN Convention on the Rights of Persons with Disabilities (CRPD) states in Article 1 Purpose, 'The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity'. DAV have used 'promote, protect and ensure' in this document and it encompasses concepts relating to 'defending' human rights also.

B.3 About this DAV submission

17. DAV welcomes the fact that 'human rights' have been identified in the Disability Royal Commission ("DRC") Terms of Reference as one of the four theoretical themes adopted in the DRC's work. DAV's submission draws substantively on the views of people with disability, many of whom have been subject to violence and abuse. Insofar as it does this, and as a peak independent disability advocacy organisation, we suggest that this submission aligns with the Convention on the Rights of Persons with a Disability (CRPD), Art29 (Participation in political and public life) (b):

'To promote actively an environment in which persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others, and encourage their participation in public affairs'.

- **18.** We also recognise the importance of other human rights Conventions, Covenants and Protocols to which Australia is signatory, and anti-discrimination laws, *inter alia*: the International Covenant on Civil and Political Rights (ICCPR), the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Federal *Disability Discrimination Act* 1992. DAV notes that the state of Victoria also has its own human rights law, the *Victorian Charter of Human Rights and Responsibilities Act* 2006, as well as its *Equal Opportunity Act* 2010.
- **19.** Furthermore, DAV would like to point out that, as discussed in our submission below, in adopting 'intersectionality' and 'life course' as two further underlying approaches, and as exemplified in its Interim Report, the DRC has:
 - a) brought into play a raft of other international conventions and national discrimination legislation (e.g. UN Convention on the Elimination of All Forms of Discrimination against Women, ("CEDAW"); UN Convention on the Rights of the Child; the UN Convention on the Rights of Indigenous Peoples; the proposed Convention on the Rights of Older Persons, as well as Federal legislation such as the Age Discrimination Act, 2004; Racial Discrimination Act 1992 and Sex Discrimination Act 1984);
 - established a narrative that makes the case about how limitations to economic, social and cultural rights lead to vulnerabilities that increase the potential of people to suffer violence and abuse;
 - c) recognised CRPD Article 11 on 'Situations of risk and humanitarian emergencies' as they relate to COVID-19.
- **20.** In this submission, DAV seeks to address the specific questions set out in the DRC's Letters Patent.
 - a) what governments, institutions and the community should do to prevent, and better protect, people with disability from experiencing violence and abuse, having regard to the extent of violence and abuse experienced by people with disability in all settings and contexts;
 - b) what governments, institutions and the community should do to achieve best practice to encourage reporting of, and effective investigations of and responses to, violence and abuse against, and neglect and exploitation of,

- people with disability, including addressing failures in, and impediments to, reporting, investigating and responding to such conduct;
- what should be done to promote a more inclusive society that supports the independence of people with disability and their right to live free from violence and abuse;
- d) any matter reasonably incidental to a matter referred to in paragraphs (a) to (c) or that the DRC believes is reasonably relevant to its inquiry.
- **21.** The focus in this submission rests largely on questions a) and b) above.

B.4 Methodology

- **22.** To address these issues and supplement the knowledge it has captured from the disability advocacy sector in its role as a peak disability advocacy organisation in Victoria, DAV has undertaken a consultation with its members and more widely across the disability advocacy sector in Victoria. This consultation has involved:
 - a. A **case study survey** distributed widely across disability advocacy organisations to identify case studies, answer questions relating to each case study, to understand what factors contributed to each incident of violence and abuse and what solutions there might be to these.
 - b. A **focus group** with senior advocacy executives and Board members these explored issues relating to systemic change, and to policy and legislative reforms required to support measures designed to address violence and abuse against people with disabilities.
 - c. A **coordinator survey** –explored the health of the disability advocacy sector and asked executive officers and leaders in the advocacy sector similar questions about the causes of violence and abuse, as well as solutions.
- **23.** DAV accepts that violence and abuse occur in numerous environments. For the purposes of this submission, we have focused mostly on disability service provision.
- **24.** Throughout this submission, advocacy refers to self-advocacy, individual advocacy and systemic advocacy. DAV understands that advocacy is an extremely important part of safeguarding.

C. Disability Advocacy - Importance, Impact and Limitations C.1 Advocacy and its impact

25. In general, people with disability experience different life opportunities comparative to people without disability. This experience of everyday discrimination and widespread physical, social and cultural barriers deprive people with disability of their human rights. Advocacy is a critical safeguard that helps prevent abuse and neglect and to uphold, promote and protect the rights of people with disability, as upholding, promoting and protecting human rights are the primary goals of advocacy.

- **26.** In Victoria, disability advocacy has a history of promoting and protecting the human rights of people with disability, and advocacy agencies have led the disability rights movement in building a fairer community for people with disability⁷.
- 27. In September 2017, the Disability Advocacy Network Australia (DANA) published a cost benefit analysis of Australian independent disability advocacy agencies, which revealed that disability advocacy has improved the capacity of people with disability to manage their lives while reducing the use of government services such as police and hospitals. It found that disability advocacy improved the lives of many thousands of people with disability, which benefits the wider Australian community⁸.
- **28.** The DRC's Interim report has also acknowledged the long-term impact and positive outcomes of activism, advocacy and the disability rights movement,

'The activism and advocacy of the disability rights movement since the 1970s and 1980s has led to substantial changes in Australian legislation, policy and practice. The achievements include the enactment of the Disability Discrimination Act 1992 (Cth) and Australia's ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) on 17 July 2008'9.

29. It is encouraging to see that the DRC's Interim Report has also recognised the role of disability advocacy in several of the areas set out in the CRPD, such as education and learning, homes and living, health, relationships, community and economic participation, and Justice¹⁰:

'We have heard about the lack of access people with disability have to education and its opportunities and benefits. Many people with disability, their families and advocacy groups describe this as neglect'11.

'...importance of strong advocacy in ensuring people with cognitive disability are provided with quality health care' 12 .

C.2 Limitations of the disability advocacy sector

30. The discussion above shows that disability advocacy is one of the measures that can help prevent violence and abuse of people with disability and has a significant role to play. However, we found in the coordinator survey, that disability advocacy is already under significant pressure. One of the participants mentioned that:

'We have increasing demand and no capacity to get anywhere close to meeting demand... This means we constantly have unmet demand'.

⁷ State of Victoria, Department of Health and Human Services, (2018). Victorian Disability Advocacy Futures Plan 2018-2020. P. 11.

⁸ Disability Advocacy Network Australia. (2017). A cost benefit analysis of Australian independent disability advocacy agencies report. https://www.dana.org.au/about/publications

⁹ Commonwealth of Australia (2020) Royal Commission into violence, abuse, neglect and exploitation of people with disability: Interim Report. Attorney General's Department Barton ACT.

¹⁰ United Nations. "Convention on the Rights of Persons with Disabilities." Treaty Series, vol. 2515, Dec. 2006, articles 12, 13, 19, 25, 22, 23, 24 27, 29 and 30.

¹¹ Commonwealth of Australia (2020) Royal Commission into violence, abuse, neglect and exploitation of people with disability: Interim Report. Attorney General's Department Barton ACT.

¹² Commonwealth of Australia (2020) Royal Commission into violence, abuse, neglect and exploitation of people with disability: Interim Report. Attorney General's Department Barton ACT,

31. At the same time, there is a feeling that cases are increasing in their complexity with all survey participants saying the complexity of cases had increased 'a lot' or 'a little'. Both expanding caseload and complexity were seen to have impacts on addressing violence and abuse:

'Access to the DSP, legal issues, for example guardianship, matters of service quality, non-NDIS service access & quality are all relatively common topics that we address. Financial abuse by extended family, neglect by services, physical abuse by family, and coercive control by the family are all recent issues we have dealt with. These can be long term advocacy issues, requiring intensive hours & commitment from staff'.

- **32.** Attempting to navigate complex and intersecting support needs where multiple service systems at state and federal levels are involved; bureaucratic procedures related to NDIS and Quality and Safeguards Commission; and siloed service systems, add to the complexity of the cases disability advocates come across.
- 33. In one such case, a 17-year-old man with an intellectual disability was removed from his home in regional Victoria by the police and was pressured to move to Melbourne with his grandparents who were negligent and failed to provide appropriate care. His mother (who was his primary carer) remained in regional Victoria and they were unable to get priority housing to be together due to long waitlists and high demand for public housing. They were both ineligible for housing support due to having current accommodation, despite it being unsafe and unliveable. The client was deemed ineligible for many disability supports due to inadequate documentation relating to his diagnoses, and child protection was not involved because of the person's age.
- **34.** This example shows how a single case can be complex, unique and challenging to manage, as it involves navigating different service systems (in this case, housing, family violence and disability) to help the client access the necessary supports. This also means increased workloads for advocates and longer waiting periods for people with disability to access advocacy and information.
- 35. The coordinator survey found that all advocacy organisations felt demand for advocacy services in the past three years had increased 'a lot' (87.5%) and or 'a little' (12.5%). Indeed, in the last three years the coordinator survey found that 63% of disability advocacy organisations had introduced waiting lists and the same percentage were referring people for information and advice, waiting to see whether, after this, the cases came back. This has caused advocates and advocacy organisations much distress. This is specifically the case for advocacy organisations that are limited by the geographical area they cover, or which cater to specific disability groups to manage demand. These findings are common across the disability advocacy sector in Victoria. DAV suggests that the increase is partly due to the regulatory bodies whose jobs are to safeguard the rights of persons with disabilities, being ineffective.
- **36.** The consultation findings also revealed that for 13% of participant disability advocacy organisations the funding had increased 'a lot' and 37% organisations reported their funding to have increased 'a little' in the past three years. 37%

reported funding as being the same and 13% said that it had decreased 'a little'. As one participant mentioned:

'We have increasing demand and have no capacity to get anywhere close to meeting demand'.

- **37.** The result is that 63% of participants did not have confidence in the future of funding for their organisation. Considering this evidence, it is important to note that if disability advocacy is to effectively address violence and abuse it will require the resources to do so effectively.
- **38.** In using case studies to address the DRC Letters Patent we highlight issues tied up with services, systems and legislation. We also use the data to systematically explore the role of disability advocacy in more detail to provide some nuance and additional evidence around the ways in which disability advocacy plays a central, but not exclusive role, in the context of addressing violence and abuse. The following section highlights a number of case studies and provides a detailed analysis of the role of advocacy in each case.

D. Key factors and causes of violence, abuse, neglect and exploitation.

D.1 Background

- **39.** DAV does not feel broad theoretical categories like life course, intersectionality and discrimination are a *direct* and inevitable cause of violence and abuse of people with disability. However, these factors do set the conditions which lead to violence and abuse. DAV feels it is necessary to explore how these factors come into play in situations of violence and abuse.
- **40.** In this section we will look at a number of case studies to identify barriers to reporting, investigating and responding to violence and abuse, followed by a detailed analysis of these barriers to recommend potential solutions and policy changes to improve the outcomes for people with disability. As the analysis of aggregate case studies proceeds in this section of the submission, we point to how and why the laws and policies presently in place do not and cannot work. This allows us to suggest solutions that address these gaps.

D2. The Case-making Period:

41. DAV collected 18 detailed and 4 less detailed case studies, for each of which additional questions were asked. Looking at these case studies, we found that a range of factors must be considered before a case of violence and abuse could even be considered a 'case' that needed to be addressed. This we call the 'case-making' period.

Reliance on Verbal Communication: A person cannot speak up

42. A reliance on verbal communication and a lack of adequate opportunities to communicate in the language and modality most appropriate to report violence and abuse can lead to people with physical, cognitive and psychological disabilities being

unable to adequately express their views and tell their story which can result in violence not being identified in the first place. The current policy landscape and the present complaints and safeguard mechanisms do not identify a victim unless they come forward and share their story. The present system does not guarantee vigilance or early intervention.

43. Persons who cannot speak up remain underserved by the system and, as a result, more open to violence and abuse. One disability advocacy coordinator mentioned that:

'people that do not have a voice, are vulnerable and unable to defend and uphold their rights' 13.

- **44.** Consultation participants identified a range of groups unable to speak up: those whose first language is not English, those with severe cognitive disabilities, neurodivergent people who are non-verbal, and those with severe or profound disabilities sufficient to impede communication.
- 45. However, even if a person can speak up, many people with disability may not recognise that what is happening to them is violence. They may not be able to conceptualise their lives in terms of their human rights. In many cases, the person might also demonstrate what has been termed 'adaptive behaviour preferences'¹⁴. This describes a situation where a person becomes so used to their situation that they see what is happening to them as 'normal' and blame themselves for what is occurring. The case study consultation found that in 61% of cases the person was 'resigned to their fate' (see Appendix 2). It was also found that in 78% of cases the 'Person with a disability lacks information and knowledge about human rights or the process to make a complaint' (see Appendix 2). Given their lack of voice in such situations, the likelihood of reporting violence and abuse reduces. Indeed, some people with disability are so eager to please they may overlook infringements to their rights¹⁵.

¹³ See also, DRC Submission, Response to the Group Homes Issues Paper, Advocacy Tasmania ISS.001.00076_0001 in which '…clients who are nonverbal are at a particularly heightened risk of abuse. Many people who are nonverbal are dependent on the service that is perpetrating the abuse', (p.4); and, DRC Submission, Response to the Group Homes Issues Paper, Melbourne East Disability Advocacy group, ISS.001.00070_01_0004, 'people who are most vulnerable are those people presenting with complex communication or who maybe non-verbal. People who are not necessarily in a position to declare or to speak out', p.5.

¹⁴ Nussbaum, M. (2001) *Women and Human Development: The Capabilities Approach*. Cambridge: Cambridge University Press.; This acceptance of how things are can even go to wanting to please or to acquiesce, whatever the person is experiencing. This is highlighted in the DRC Submission ISS.001.00087_0001, Response to the Criminal Justice System Issues Paper by the Australian Human Rights Commission, p.22 in which a person asks for reassurance they are a "good boy/girl" and to write it in "the book".

¹⁵ See para [18] Advocacy for Inclusion, DRC Submission Response to the Group Homes Issues Paper.

46. In a similar way, in our focus group with advocacy leaders, we found that a number of people would not speak out because they had become used to sub-optimal services¹⁶,

'For a lot of deaf and hard of hearing people they have gone through education and accessed healthcare in ways that we would consider to be very sub-optimal. So, they don't have that awareness that these methods are not actually appropriate'.

- 47. As a Victoria-based organisation, DAV can only comment on the Victorian situation in terms of preventative and proactive services that can monitor and report on people with disabilities in their home or work environment. Although Victoria has the Office of the Public Advocate Community Visitor Program, it is staffed by volunteers and does not have funds for Auslan Interpreters, Deaf-Relay Interpreters, Deaf-Blind Interpreters or Communication Support Partners. Despite these limitations, incident reports and complaints made by Community Visitors has resulted in the closing of a number of Victorian institutions providing inadequate services to people with disabilities and they have played a crucial role in highlighting issues of abuse and violence in the sector.
- **48.** Given the importance of violence against people with disabilities and their vulnerability due to isolation and other factors, relying on underfunded volunteer programs, in our view, is inadequate and inappropriate. We believe that the government should adequately fund services like the Community Visitors program, embedded in the Office of Public Advocate (OPA)¹⁷, with legislative powers to monitor, report and investigate quality of services provided to people with disabilities in accommodation facilities. The Independent Third Person program is another voluntary program by OPA, where volunteers attend police interviews for adults and young people with cognitive disability to ensure that they are not disadvantaged during the interview process¹⁸. This provides a crucial safeguard for the protection and promotion of the human rights of people with disability and DAV maintains that such programs must be appropriately funded by the Commonwealth government and implemented nationally (Recommendation 1).
- **49.** Apart from the communication barriers discussed above, DAV found that there are multiple reasons why people do not speak up, even where they can. This includes:
 - a) fear of the perpetrator;
 - b) fear of staff reprisal (whether the fear is realistic or not);
 - c) fear of losing services and being left more vulnerable;
 - d) a lack of trust in formal complaints services and systems;

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¹⁶ In this submission we have not been able to list all issues across service settings. In the DRC Submission, Health Issues Paper, Inclusion Australia ISS.001.0388_01_002 sets out several issues around violence, abuse, neglect and exploitation of people with disability in health settings as well as the recalcitrant health inequalities experienced by people with disability for many decades. In relation to Health Issues Paper the Lowitja Institute ISS.001.00228_01_0001 makes a submission about the intersection with First Nations People demonstrating lack of community health-controlled organisations and cultural and racist barriers as well as even worse health outcomes which need addressing.

¹⁷ The Office of the Public Advocate (OPA) is a Victorian statutory office, independent of government and government services, that works to safeguard the rights and interests of people with disability. The Public Advocate is appointed by the Governor in Council and is answerable to the Victorian State Parliament. https://www.publicadvocate.vic.gov.au/

¹⁸ https://www.publicadvocate.vic.gov.au/opa-volunteers/independent-third-persons

- e) the formality of the process; and
- f) fear of not being believed.
- **50.** The most common reason why people do not speak out even though they know they have been subjected to violence and abuse is because often the person is terrorised or fearful of the perpetrator(s).

In a case of family violence, the client was:

'a woman in her 50's with an Acquired Brain Injury (as a result of stroke) and was subjected to entrenched family violence. She used a wheelchair and had speech impairments because of the stroke and was dependent on the perpetrator for all her support needs. After the hospital-based rehabilitation service lodged an application for a financial administrator to be appointed, her partner was appointed financial administrator by the Victorian Civil and Administrative Tribunal (VCAT). The woman was unaware there was a VCAT hearing and found out by chance several years later that there was an Administration Order. Eventually she became a NDIS participant, and through building a trusting relationship with her support coordinator and a lead worker over some time, she was able to feel safe enough to disclose she was being abused'.

And, in another case,

'A client living in a boarding house was subjected to verbal and some physical abuse from one resident and also isolated by the others because the perpetrator was very intimidating. The client felt unable to cook their traditional food because the other residents complained about the smell. There was no respite for the client during COVID-19 lockdowns because all residents are at home all day and the boarding house manager did not allow visitors (including support workers). The client felt unable to use any shared facilities - kitchen etc. and was toileting in a bag in his room and emptying it at night when everyone was asleep. NDIS wouldn't provide emergency accommodation because the client was already housed. There were limited options for the client in seeking alternative accommodation due to the prohibitive cost, and housing shortages'.

- **51.** The case study survey found people were frightened to speak up in 43% of cases. It must be remembered that in the case studies shared in this document people *did* eventually speak up. Based on its knowledge of the disability sector, DAV believes the number of people who do not speak up is much larger and that these cases of violence and abuse remain unknown and unrecorded.
- **52.** In two of the reported case studies, COVID 19 lockdowns also had a negative impact by extending the time the person subject to violence and abuse was required to remain in contact with the perpetrator.
- 53. Another significant reason people do not speak up is that they are concerned about the outcomes of doing so. DAV members know of countless cases where people with disability have a fear of complaining about staff in case they retaliate. While this did not feature in the DAV consultation case studies, it remains an issue nevertheless.

54. People can be fearful of other outcomes. In one situation in a Supported Residential Service¹⁹ (SRS) setting, the person did not speak out due to fear of the consequences. One advocate reported that the:

'client was too afraid of being homeless if he complained'.

- 55. In this case it is important to note that the person was willing to sacrifice him/herself (Art. 16 Freedom from exploitation, violence and abuse and abuse, CRPD) to ensure another of their human rights (Art. 19a relating to a place of residence, CRPD). It should also be noted that the person's perception was not about 'choice of residence' as referenced in the CRPD it was about simply not having *anywhere* else to live, i.e. being homeless. This references the issue of housing choice mentioned by the DRC²⁰ and discussed later in this document.
- **56.** The case study survey also found that trust in services was very important. If a person experiencing violence and abuse had lost trust in the service, then they were less likely to report it. For instance, for a person being verbally abused and physically threatened by another resident in a boarding house:

'One of the issues was the client's lack of trust in agencies (especially government agencies)'.

- **57.** It has also been found that if a person complained previously, but nothing was done, this too leads to a lack of trust and a reduction in making complaints²¹.
- **58.** In the case study consultation, it was found in 61% of cases that the 'Person with a disability was frightened to speak up'.
- **59.** Indeed, we found in the case studies that staff were also 'frightened to speak up' in 43% of cases (Appendix 2). When staff are scared to speak up this increases the likelihood of violence and abuse, particularly for those who have nobody else in their network to support them. The case studies only address the reported cases of violence and abuse. One can only wonder what proportion of unreported cases are not addressed as a result of such fear.
- **60.** Another important issue is when a person speaks up but is ignored, not believed, or seen as an unreliable witness.

¹⁹ Supported Residential Services (SRS) are privately owned businesses that offer accommodation and support to people with disability under the Supported Residential Services (Private Proprietors) Act 2010. There were 129 services from small to 80 residents in Victoria in 2018. https://www2.health.vic.gov.au/ageing-and-aged-care/supported-residential-services/srs-overview

²⁰ DRC Submission, Response to Issues Paper on Group Homes, Independent advocacy South Australia, Inc, 188.001.00187_01_0001, 'People who live in a group home typically have no choice or control in terms of who they live with, where they live, who supports them, what support they receive, their daily routines, nor their food/drinks. When the circumstance/routine does not fit for an individual person the service commonly defines them as the problem and the person is labelled as difficult, picky or lazy; as opposed to the support being poorly structured and not providing the person with genuine opportunity', p.2 [6].

²¹ Ramcharan, P., Nankervis, K., Strong, R. and Robertson, A (2009). Experiences of restrictive practices: A view from people with disabilities and family carers. Department of Human Services. (DHS): Melbourne.

61. The DAV case study consultation found that for many people who had spoken up to staff in disability services, their voices had not been heard²². For example, 'A woman had experienced violence and abuse from a support worker. She had told the support service many times. It was not until her family reported it that the service stopped the worker from going to her home'.

62. In another case:

'As the complaint went on there were other incidents...I mean Dionne²³ was out of [disability provider's] accommodation. She had to recover and return to [disability provider's] accommodation. She kept reporting issues. The family said the incidents were her being verbally abused by her workers and whenever they made complaints to [disability provider] that Dionne had reported it they said that they would talk to the support workers'.

- **63.** The effect of ignoring the client's complaint can be devastating:
 - "...the SRS response was to not believe my client and leave her residing with the perpetrator. They [the client] eventually ran away²⁴ leaving them homeless and at a high risk of further assault'.
- 64. 74% of cases submitted in the case study survey indicated that the person with a disability had spoken up but been ignored²⁵ (see Appendix 2). Furthermore, in 68% of cases, the person was seen to be an unreliable witness (see Appendix 2).
- 65. As the Disability Royal Commission proposes, attitudes toward people with a disability play a major role in them not being believed. In the DAV case study survey, 91% of participants felt that the

'Perception of others (discrimination, negative attitudes, ableist thinking, stigma)...means the person's rights [are] not recognised and actions taken' (see Appendix 2).

- **66.** The attitudes of others to people with disability can be a key factor in whether their complaint is ever addressed. People with disability need to be believed. Many will require independent support to have their complaint accepted ²⁶.
- 67. DAV believes that many of these barriers to communication can be overcome with the appropriate supports in place. When supported, people with disability can not

²² See also DRC Submission on Group Homes Issues Paper by Advocacy for Inclusion in which the service had an external agency carry out an "investigation" finding "insufficient evidence" of sexual assault (paragraph [15])

²³ Pseudonym used here

²⁴ It is assumed this means the service of the SRS was withdrawn.

²⁵ See DRC Submission on the Group Homes Issues Paper, Advocacy Tasmania ISS.001.00076 0001, 'Often people will experience a tokenistic promise that 'things will change' but then find several months later that nothing has changed, and they are still living with violence, abuse or neglect', (p.4).

²⁶ In this section of the submission and the views of people with disability discussed previously can be seen to have been systematically ignored. Yet the NDIS Effective Complaint Handling Guidelines specifically say that, 'P7. Empowering people to speak up goes to the very heart of people feeling valued and respected as equal citizens in their community' (p.7) and that 'The person making the complaint, and any person with disability affected by issues raised in a complaint, should be included throughout the process to the extent possible' (p.8). Neither of these are evident in the way complaints are handled currently, raising the limitations of self-regulation.

only communicate but with supported decision making they can also make decisions about their lives that reflect their will and preference. In the case study consultation, 70% of participants strongly agreed with the statement that 'No supported decision making has taken place' while 100% of participants spoke of the need for more supported decision making²⁷. This indicates a gap in supporting people who would not otherwise be able to communicate their experience of violence and abuse.

- **68.** Supported decision making supports people to express their will and preference about key areas of their lives. When supported decision making is used regularly people will have more of a chance to express issues they are experiencing with violence and abuse. Disability services and schools, supported by speech pathologists where required, have a key role to play in making sure each person is provided with the best method to support them in communicating.
- **69.** It should be noted that supported decision making is not equivalent to supporting communication, which is ensuring that a person has the tools and environment they need to use their chosen method of communication. Supported decision making refers to the process of, and assistance to, an individual that is required for expression of their will and preference in decisions fundamental to independence, agency and dignity.
- 70. A person may need assistance with both supported decision making and communication. Based on the discussion above, we recommend enacting a Commonwealth Communication Bill of Rights which: enshrines the rights of people with disabilities to be taught how to functionally communicate through the method of their choice and require disability service providers, including schools, to commit to accredited Auslan Interpreters; accredited Deaf-Relay Interpreters, accredited Deaf/Blind Interpreters and accredited tactile Auslan Interpreters; the provision of evidence-based literacy programs for those with language/learning disorders; and for people with little or no speech - Communication Partners, the provision of devices, accredited trainers, and the facilitation of the use of devices in all settings, at all times (Recommendation 2).

Isolation

71. A major additional indicator closely linked to the above cases of violence and abuse in which complaints from the person with a disability were not heard, occurred in situations in which there was isolation²⁸. One of the advocates shared a case where the client was

'extremely isolated by the time she engaged with advocacy (no contact with siblings or long-term friends nor even in the local community). Family and friends stopped visiting as they were turned away by the perpetrator'.

²⁷ DRC Submission, Issues Paper on Group Homes, Women with disabilities Australia, ISS.001.00242 0002 with which we agree; 'In line with the jurisprudence and recommendations of the CRPD Committee, Australia should withdraw its interpretative declaration on article 12, replace substitute decision making mechanisms with supported decision-making, and implement a nationally consistent supported decision-making framework', (para. 12).

²⁸ DRC Submission, Response to Group Home Issues Paper, Purple Orange ISS.001.00369 01 0001 state similarly that, 'The consequence of low Social Capital is isolation and loneliness, and in extreme cases, heightened vulnerability of abuse and neglect' (p.19).

72. When asked what could have been done to encourage or support earlier reporting of the case one person said:

'If the woman had had stronger networks at the time the violence and abuse started to occur, and/or, if the service had valued her voice and safety'

- **73.** Another barrier identified in one of the cases was: 'Having no family or friends and relying on one service provider'.
- 74. In the DAV survey which considered solutions to violence and abuse, one solution which rated highly was that 'No one disability service having a sole or majority "ownership" of or engagement with the person with disability'. 79% strongly agreed and 17% agreed with this statement (Appendix 3). In terms of the case studies, it was found that 57% agreed that 'power being in the hands of just one service provider or worker' had contributed to violence and abuse (Appendix 2). 'Regional and rural services dominated by singular disability service providers' is also considered to be a major issue.
- **75.** The case study survey of factors contributing to violence and abuse identified: 'isolated from other supports and a confidante capable of responding to the issues' in 65% of the cases; 'limited or no community supports' in 82% of cases; 'having few family and friends' in 65% of cases; and 'power in the hands of just one service provider or worker' in 57% of cases (Appendix 2).
- 76. Isolation does not only occur due to people not being physically close to others. The segregation of many people with disabilities starts in school, meaning that many general members of the community reach adulthood without having ever met a person with a disability. Their further segregation in day centres and sheltered workshops (also known as Australian Disability Enterprises (ADEs)) separate them from the general community. This often leads to a level of discomfort and genuine confusion as to how to communicate with a person with a disability, especially those with moderate to profound disabilities, even from people with the best of intentions.
- 77. When children with and without disabilities grow up alongside each other, and adults with and without disabilities work beside each other, then people with disabilities take on a "normality" that encourages those without disabilities to regard them as just other members of society, like themselves, and engenders relationships that will lessen isolation and promote communication (Recommendations 3, 4 and 5).

Poverty

78. In the lives of most people, changing their circumstances to escape violence and abuse may take money, for example changing homes, or changing their employment. What we found for many people with disabilities is that they do not have the personal finances, much less the level and type of support required, to put them in a position of safety. The NDIS and the service systems in place often do not

support a person to choose or change their home, education and services sufficiently in circumstances of violence and abuse.

Behaviours of concern

- **79.** People whose voices are not heard and whose rights are not successfully promoted, protected and ensured, find their situation extremely difficult. In such circumstances, and in order to communicate their protest and their resistance, they may show behaviours of concern.
- **80.** Many of these behaviours are perfectly legitimate if there is no other way to communicate what has happened to them, or if no one listens to their complaints. Sometimes their views can be de-legitimised because of these behaviours. In such circumstances applying a "consequence" driven behavioural support plan (regrettably the most common type) to address such behaviours leads to double disadvantage, that is, the violence and abuse itself, and then using punitive behavioural techniques (often violent techniques such as restrictive practices) to silence their legitimate protests.
- **81.** There should be a requirement to look at violence and abuse as one possible and important cause of such behaviours.
- **82.** Behaviours of concern are learned and can occur predictably when people with disabilities have no functional communication, when they are being mistreated, when their behaviours of concern have been negatively reinforced, for reasons linked with sensory overload, and for other reasons which people who work in the disability sector should be cognisant of and should know how to address.
- **83.** Auslan and sign language can be misunderstood as a behaviour of concern (i.e. someone waving their arms may be read as aggression). Deaf and hard of hearing people may also do things such as tap feet on floor to get attention, knock hands on the table to get attention or tap someone on the upper arm. These things can incorrectly be read as aggression or assault
- **84.** There are times when understanding what is behind behaviours of concern requires a sophisticated process from someone who has a qualification in behavioural science.
- **85.** All too often, those that provide services to adults and children with disabilities respond to behaviours of concern through unqualified staff, punitive measures, and restrictive practices. The research on punitive measures and restrictive practices is prolific and indicates that such responses worsen behaviours of concern. Responding to behaviours of concern is seen by many organisations as something that almost anyone can do. For example, the Victorian Department of Education and Training has this to say about who can undertake a Functional Behaviour Assessment:

An FBA is not necessarily a clinical undertaking and does not have to be conducted by a person with specific qualifications²⁹

- **86.** DAV submits that this sort of experimentation on people with disabilities would never occur in the broader community. Those in the broader community demand and enjoy appropriately qualified practitioners, for example, medical and allied health practitioners, with qualifications in the relevant areas of expertise. There is rigour applied to which professional has the skills to address various medical/psycho deciding social issues. Given behaviours of concern can result in serious injury and trauma to the person displaying the behaviours (e.g. self-injurious behaviour) and others, encouraging unqualified/underqualified/inexperienced persons to address these issues should be viewed as a serious ethical and human rights breach that it is.
- **87.** In a case in an education setting a child was restrained without written approval detailed in an authorised Behaviour Support Plan (BSP). In the focus group, one person stated in relation to restrictive practices, that
 - '...the people who are supposed to provide behaviour support plans are totally not qualified. And so again, here are people being forced into situations completely out of their control and which are against anybody's standards of human rights'.
- 88. The most recent NDIS Commission Activity report of the Quality and Safeguards Commission³⁰ shows that the largest number of complaints relate to the use of unauthorised restrictive practices. DAV identified many such unauthorised practices in adult services, and schools³¹. As mentioned in the Executive Summary, it was reported that NDIS providers used unauthorised restraints on clients more than 1 million times in 2020-2021³². One can conclude that the NDIS's system of registration of behaviour practitioners is failing, as these practitioners do not have the skills to effectively mitigate the behaviours of concern that are severe enough that service providers are responding with chemical restraint and violence. There is currently no minimum qualification for registration through the NDIS as a "behaviour practitioner". There is no Australia wide regulatory system or requirement to use evidence-based approaches to respond to behaviours of concern. While Board Certified Behaviour Analysts are regulated by the Behaviour Analyst Certification Board, there is no impediment in Australia to anyone calling themselves a "behaviour analyst". Therefore, there are no entry-level standards of practice, compulsory code of ethics, standards for continued professional development or single application process across Australia. Given the harm these

²⁹ Victorian Department of Education (2020) School Operations Behaviour – Students 7.

https://www2.education.vic.gov.au/pal/behaviour-students/guidance/7-functional-behaviour-assessment

³⁰ NDIS Quality & Safeguards Commission (2022) Activity Report 1 April – 3- June 2022

https://www.ndiscommission.gov.au/sites/default/files/2022-09/Activity%20Report%20Apr%20-%20Jun%202022.pdf

³¹ DRC Submission to the Education Issues Paper, Autism, Asperger's Advocacy Australia, ISS.001.00054_01-0028. In DAV Inc submission we have only been able to cover a few issues but it is noteworthy that this submission talks about 'A catalogue of segregation, exclusion from school activities, suspension and expulsions and gross inadequacy of behaviour support, inflexible curricula, workforce capability issues and violence and abuse'

³²Henriques-Gomes, L. (2021, November 10) 'NDIS providers used unauthorised restraints on clients over a million times in 12 months' *The Guardian: Australia Edition https://www.theguardian.com/australia-news/2021/nov/10/ndis-providers-used-unauthorised-restraints-on-clients-over-a-million-times-in-12-months*

unauthorised practices can cause to people with disability, it is essential to ensure that only appropriately qualified and trained people enter the disability workforce as "behaviour practitioners" (Recommendation 6). We also recommend that the regulation of "behaviour practitioners" be taken away from the NDIS Quality and Safeguards Commission and given to the Association for Behaviour Analysis Australia in order to protect the community from unqualified persons claiming they can effectively mitigate the behaviours of concern (Recommendation 7).

- **89.** There has been no data that supports the reduction or elimination of restrictive practices since the 2014 'National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector'. Given that this "framework" was limited in application in any event (for example, it did not cover restrictive practices used in schools) it suggests that the endorsement by the relevant state and territory disability Ministers was a result of a preference for form, rather than substance.
- 90. Restrictive practices (or assault and false imprisonment), which we know cause injury, death and trauma, should largely be viewed as the result of incompetent treatment, violence and abuse, or inadequate support of the person with a disability. Therefore, the reduction/elimination of restrictive practices must be more than a wish, it ought to be a priority within an immediate short timeframe, given how many years that this has been part of policy for numerous organisations and various government departments.
- **91.** We believe that restrictive practices in all settings must be prohibited unless recommended and applied by qualified behaviour analyst³³, and to discourage the use of unauthorised restraints, significant fines should immediately be applied against service providers, except in cases of extreme emergencies (i.e. serious selfinjury) (Recommendation 8).
- **92.** In the context of the National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector failing to achieve its aims, DAV also endorses the rrecommendations 10, 11, 12, 13 and 15 of the submission dated 6 October 2020 from the Disability Discrimination Legal Service to the Disability Royal Commission.

Responsibility of the service provider's staff to identify violence and abuse and make a formal complaint

- **93.** Often in cases of violence and abuse experienced by a client, it is considered the responsibility of the service's staff to make a formal complaint about the issue and pursue it on behalf of the person with disability.
- **94.** Disability advocates in Victoria revealed in the consultation that many support staff simply did not have the 'time and energy' and were already 'too stressed' to feel

³³ Association of Professional Behavior Analysts (2009) 'The use of Restraint and Seclusion as Interventions for Dangerous and Destructive Behaviors https://cdn.ymaws.com/www.apbahome.net/resource/collection/1FDDBDD2-5CAF-4B2A-AB3F-DAE5E72111BF/Restraint_Seclusion_.pdf

able to pursue complaints on behalf of their clients. Lack of staff training in human rights approaches was seen as a hindrance, and there was a perceived gap in this area. Indeed, in 78% of the 20 case studies, participants found a contributing factor to be 'confusion amongst service staff about what a human right is in practice' (Appendix 2).

- **95.** Staff make decisions to take things further based on hunches, observations, or disclosures. But analysing whether something constitutes a formal complaint can only work well if staff understand clients' human rights and know when these have been infringed. Further, staff must successfully identify when the threshold has been reached to make a formal complaint, as opposed to dealing with the issue there and then or, for example, completing an Incident Report. There seems to be a lack of clarity at this level as to where the threshold sits about taking an issue further.
- **96.** The DAV consultation survey found in 65% of cases the person with a disability was subject to microaggressions such as low-level bullying, harassment, verbal warnings, limitations etc. In 70% of case studies, it was perceived that 'informal and non-recordable restrictions [were used] to control the person³⁴. Further in 73% of the DAV case studies, it was found there was a 'lack of focus on everyday rights (e.g. access to toilets, drinking and clean clothes)'.
- 97. Such control of people with a disability seems quite common. It is possible that, when considered holistically, these factors may place significant controls on people with disability and affect their life quality. Where consistently employed they may even indicate a service culture that leads to violence and abuse. It was somewhat reassuring that only 36% of DAV consultation respondents strongly agreed that 'There was a culture within the service that was likely to lead to violence and abuse.'
- 98. The above point links to the importance of issues of service quality³⁵ and understanding of where the threshold is set as to when an observed or reported issue should be taken further by staff. We believe one of the solutions would be to ensure that disability service providers cannot receive registration through the NDIS unless they provide human rights training annually to staff to ensure they have a contemporary understanding of practices and procedures in place to safely report instances of violations and violence and abuse (Recommendation 9).

³⁴ DRC Submission, Response to Group Home Issues Paper, Purple Orange ISS.001.00369_01_0001 refer to the controlling behaviour in group homes; 'residents in a group home may all be required to eat their meals at the same time as more support workers are rostered on then, instead of when the residents choose to eat. This controlling behaviour by staff can escalate to the exercise of restrictive practices, such as locking fridges over night or dispensing medications to all residents at the same time, despite some medication needing to be

carefully timed around food consumption'. Similar sorts of control and informal restrictions will be applied, but in different ways, in other congregate service settings.

³⁵ DAV Inc is not in a position to systematically address issues of service quality and believe these will be addressed in other submissions and notably in several DRC Issues Papers which can be found at:

https://disability.royalcommission.gov.au/policy-and-research/issues-papers We limit ourselves to issues of service quality pertaining to the DAV Inc case studies and to the procedural issues consequent to these.

Obstruction by service providers

- **99.** It must be recognised that disability service providers across many sectors (support, housing, education, employment and so forth) are not independent of conflicts of interest³⁶ and it is a possibility that complaints against their organisations are intentionally ignored and the issue remains unidentified.
- 100. Without support, many people with disability have extraordinarily little power over service systems and regulations. The service systems and regulations have been designed to prevent many people with disability from exercising their own autonomy. This means that it is possible to prevent complaints from being recognised, to deal with them informally or use procedural means to resist them from being pursued.
- **101.** The DAV consultation found several cases of limitations on rights of access to services. In one of the case studies, a boarding house landlord was not allowing visitors, including the person's support workers³⁷, even though the person was being threatened with violence and abuse³⁸.
- 102. For another young person in secure accommodation:

 'He had not been back to his family house even for a visit so it was like he was just locked in and even on outings he would not be allowed out of the van. It was extreme'
- 103. The DAV consultation also found in 55% of the cases (Appendix 2) that the person with a disability had no means of contact with advocacy organisations and so the prospect of achieving equal power/standing was further tested unless the person had family, friends or others who could support them when necessary. This highlights the process through which the isolation can have a greatest impact. Indeed, not allowing such contact leads to further isolation which, as already suggested, is a major factor contributing to violence and abuse against people with disability.

Final Remarks: The case-making period

104. The contents of this section speak of people who have experienced violence and abuse and who never appear in official statistics on violence and abuse. The findings

³⁶ DRC Submission Response to the Group Home Issues Paper, Advocacy for Inclusion, ISS.001.00187_01_0001, who argue that in group homes '...the conflict of interest between the best interests of the individual versus the service provider, versus the group interests is an ongoing concern in most, if not all, situations'. [22]. The issue of conflicts of interest are also recognised in the DRC Interim Report (op cit) in relation to group homes 'It is hardly surprising that conflicts or other difficulties can arise when people are forced to live together' (p221) and this combines with vulnerability, since ', but can leave a victim of abuse with no option but to continue living in the same accommodation in which the perpetrator works or lives' (ibid).

³⁷ DRC Submission Response to Issues Paper on group Homes Queensland Advocacy Inc ISS.001.00216_01_0001 – 'Complaints to Department of Housing and Public Works about dubious and unethical behaviour of hostel and/or boarding house operators does not constitute an infringement of their accreditation as a provider of accommodation'.

³⁸ In the *Reportable Incidents: Detailed Guidance for Registered NDIS Providers*, June 2019 it is stated that, 'Each participant is provided with information about the use of an advocate (including an independent advocate) and access to an advocate is facilitated where allegations of violence, abuse, neglect, exploitation or discrimination have been made' (p.7). Clearly this does not always work and does not apply in the same manner to non-NDIS registered services.

point to people who have been systemically denied resources to access the complaints procedure and who are ignored or seen as unreliable witnesses.

105. The findings also point to people whose poverty as well as choice and control over services are insufficient to give them the option to leave their situation. In some circumstances, behaviours of protest against the violence and abuse they are experiencing can be responded to through punishment or incompetence. There are major service gaps, systemic issues, as well as a lack of advocacy faced by these people. Victims of violence and abuse are often powerless to do anything about it and, drawing on the Statement from the Heart³⁹ with the utmost respect, we see the situation of such victims as the 'torment of the powerless' - being entrenched in structural and systemic disempowerment.

D3. Barriers Created by Disability Services

- **106.** The survey of contributing factors to violence and abuse found that 70% of cases were perceived to be linked to inadequate services and oversights due to a lack of funding, as well as 'lack of individual plans and supports to achieve the person's goals' in 65% of cases (Appendix 2).
- 107. Conflicts of interest were also seen to contribute to violence and abuse.

 'We have a client whose accommodation provider is also their support provider.

 [The client is] getting billed. But we don't think they are getting a service and this particular client wants to move out and there's been no attempt... it happens again and again. So I guess it's financial abuse as well as human rights abuse'

108. As one advocate explained:

'Regarding the services themselves, I think the key issues are...staffing, conflict of interest, lack of rights-based training, culture of control, lean funding models taking the focus away from the needs of clients and onto business sustainability and profit'.

- **109.** If these providers are meeting the service quality standards, and violence and abuse still occurs (which it does) then these standards are a blunt instrument when it comes to client safety. DAV believes that the issue is not only an argument for 'the importance of establishing rigorous quality assurance systems and external monitoring of disability services and safety protocols' ⁴⁰ as it is about the independence of monitoring and what is being monitored.
- **110.** A critical safeguard in this context could be that the Victorian Disability Worker Commission model is adopted nationally, with the registration being mandated rather than optional, to enable a central register for disability workers as it would help minimise the risk of harm and neglect to people with disability by ensuring

³⁹ Uluru Statement (2017) 'The Uluru Statement from the Heart' https://ulurustatement.org/the-statement

⁴⁰ Commonwealth of Australia (2020) Interim Report: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Barton: Attorney-General's Department. October 2020, p223

access to safe and quality services and skilled and professional disability workers (recommendation 10).

111. Many found the Quality and Safeguards Commission to be "toothless" and to be too closely connected to the NDIS, which is part of the service system. Indeed in the consultation on solutions to violence and abuse, DAV found that 88% of participants strongly agreed and 12% agreed, that there was a need to 'Get rid of 'toothless' policies around safety, protection, quality and safeguarding' (Appendix 3). As one exasperated participant put it:

'we don't need towers with commissioners sketching conceptual models and capabilities frameworks, we need people on the ground building up the networks and value and so on of PWD, and listening to their voices.'

- 112. The complaints function of the NDIS Quality and Safeguards Commission seems to have the highest investigative power⁴¹, but it has been hard to see any positive outcomes for people with disabilities who are subject to abuse and neglect as an outcome of these complaints. While the Commission has powers to conduct an inquiry into both systemic issues in relation to reportable incidents or individual events and to 'authorise an inquiry in relation to a series of complaints that have occurred in connection with the provision of supports or services by one or more NDIS providers'42, it is not done in practice. In one such case reported by an advocacy organisation, the Commission failed to take any action regarding the same issue reported by the advocacy organisation for two different clients living in the same residential service: 'it is their [commission's] responsibility to talk to other people if they are at risk of violence and abuse as a result of getting same service or living in same residence but they don't have such mechanism.' Currently the Commission does not make full use of the extent of their reach, monitoring and enforcement powers. We believe that greater emphasis needs to be placed on proactive monitoring of provider performance by the NDIS Quality and Safeguards Commission and appropriate processes must be in place to identify and address concerns and recurring complaints around particular services (Recommendation 11).
- 113. DAV did find disability service providers willing to start with internal inquiries. However, this was sometimes not without problems. In one case support workers had been stood down after a complaint. Following that the person was later rushed to hospital with a diagnosis of starvation and dehydration a basis for another complaint. But as the disability advocate says the

'...<disability provider> [would] not take responsibility. They said, "we did not have up to date feeding plans and up to date information. The family didn't give us that". And I said "That is your responsibility to request that. It's your responsibility. You're providing a quality service and if you can't do it you need to refer or find another service that can'.

⁴¹ National Disability Insurance Scheme (Incident Management and Reportable Incidents) Rules 2018.

⁴² National Disability Insurance Scheme (Incident Management and Reportable Incidents) Rules 2018.

- 114. It is important to consider and understand when discrimination or lack of support turn into "violence and abuse". One of the examples of this would be the long-standing practice of taking children away from people with intellectual disabilities causing lifelong trauma. Similar to, and concerning, the Stolen Generation, this approach to parents with intellectual disability, instead of the provision of timely and competent support, we submit, ought to be seen as constituting neglect, and institutional and psychological abuse of both parents and children. This approach also breaches many human rights.
- 115. For example, in our focus group one person explained that, with support, parents with intellectual disabilities could provide their baby and child with quality care. 'The language to be able to access child protection is when the child is "at immediate risk" and often these kids are not at immediate risk...there is a young couple with a new baby who does have all the supports in place and yet they are still being hounded based on their intellectual disability'...The first thing they know is when child protection turns up in the hospital and says "we've got concerns about the safety of your child"... So all the assessments that are put in place effectively rack up to count against them rather than to say, "with these supports it could work'.
- **116.** The fact that the medical model underlies such assessments of parents with intellectual disabilities raises a systemic issue around using outdated methods. However, these experiences also intersect with a lack of funding for appropriate support capable of maximising the chances of successful parenting.
- **117.** DAV recognises that ultimately the actions of taking children away from parents are enacted by the government. However, a range of disability/ generalist organisations are often complicit, making notifications unnecessarily. These actions are sanctioned by the government and not seen by them as constituting violence and abuse.
- 118. It is critically important that adequate supports are in place with parents with disability to take care of their children before any child is removed from his/her parents (unless that child is in extreme danger) and policies are in place regarding the respect for home and family, in compliance with Article 23 of the United Nations CRPD (Recommendation 12).
- **119.** The last two sections show a significant number of factors that contribute to violence and abuse, and a myriad of barriers that result in the violence and abuse not being identified and addressed. The compounding factors we have outlined can be viewed as a form of institutionalised discrimination⁴³.

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⁴³ DRC Submission in response to the Group Homes Issues paper, PWDA - ISS.001.00217_01_0001, 'This widespread tendency to downplay and re-frame violence and abuse as 'abuse' or as a 'service incident' results in denying people with disability the legal protections and justice extended to other people' (p.12).

Pursuing a Case involving Violence and Abuse

- **120.** In the section above it has been shown that getting a case of violence and abuse to be recognised as a formal complaint in which there is a subsequent investigation, is a significant problem. Once identified, pursuing the case can start a lengthy process involving a number of complicated processes to be undertaken by advocates to promote, and protect rights of people with disabilities. This process can involve complex form-filling and can be adversarial.
- 121. If the complaint is not addressed satisfactorily within the service complaints system, there are many formal mechanisms, at both state and federal levels, that might be pursued. Complaints in Victoria may be made to the Disability Services Commission concerning Victorian disability services, to the Victorian Equal Opportunity and Human Rights Commission (VEOHRC) concerning discrimination, and to the Victorian Ombudsman in cases relating to the Victorian Charter of Human Rights and Responsibilities. At the national level, the NDIA has complaints and review processes relating to registered participants, while complaints about NDIS registered services can be made to the NDIS Quality and Safeguards Commission⁴⁴. The Australian Human Rights Commission can take complaints relating to the federal Disability Discrimination Act (1992)⁴⁵. In some circumstances, the police can also address the situations in which the law has been broken.
- 122. Each of these processes involve writing a complaint or providing evidence and may take place over an extended period. Ninety-five per cent of the DAV case study consultation participants felt there was a need to reduce 'complex bureaucratic form-filling (Appendix 3) while, for the case studies in the survey, 64% reported that the complexity of the case meant it was difficult to resolve quickly (Appendix 2). Further, for many people with disabilities, it is vital to have the right support to make the case, which can be delivered by legal or disability advocates. Time for investigations, supporting the person with a disability to have equal access to justice, and the cases and judgements that follow, may carry significant monetary, as well as emotional, costs.
- 123. The system of making a complaint to the right authority takes time as does submitting evidence. Authorities usually do not have the skills or understanding of people with disabilities, their communication needs, and how to enable decision support. They often assume a lack of capacity without evidence of the same. Many people with disability find this process difficult and may need support/advocacy to help them speak up. The system is top-heavy in administration and much of this is in complex, and not plain, language. The system places the complainant against the perpetrator and therefore implicitly relies on an adversarial model.
- **124.** It has been argued that these mechanisms and the time taken to achieve justice weigh heavily on the complainant and can be disempowering. When violence and

⁴⁴ NDIS Quality & Safeguards Commission (2022) 'How to make a complaint' https://www.ndiscommission.gov.au/contact-us/makeacomplaint

⁴⁵ In addition, given Australia is a signatory to the CRPD a complaint may be made to the relevant Committee once all national mechanisms have been exhausted.

abuse have taken place, the last thing the person wants is the stress of a bureaucratic system. We found in the consultation that complaints bodies do not refer people to other organisations to provide emotional support and counselling when a person has been subject to violence and abuse. Our consultation shows that such systems of support for people with disability during this process need to be strengthened and applied more systematically.

- **125.** A person with a disability who has been subjected to violence and abuse needs emotional support. When they complain this can also raise their stress levels and be a trigger as a result of the violence and abuse they have suffered. Referral pathways are needed to ensure that people have access to skilled professionals. The DRC model of support, where the availability of trained professional emotional support is referred to on every occasion to people making submissions is one good example of how this can be achieved.
- **126.** We have found that while services can employ and afford strong legal teams, the same is not the case for the complainant.

Systemic Barriers

- **127.** The DAV consultation found several cases where the system presented barriers and obstruction to people with disability reporting violence and abuse. In some cases, this was seemingly used as a mechanism to prevent a case from becoming more formal⁴⁶.
- 128. In one case, a client was admitted to the hospital with fractures and the family felt that the manual handling was rough in the supported accommodation where he was living and the support workers weren't appropriately trained. An internal inquiry by the disability service provider was undertaken and 'the disability provider in their investigation found that there was no evidence that it was because of the support workers' handling but they agreed to update the manual handling training'.
- **129.** In another case, a client continued to complain about verbal abuse by staff, but when the family complained, management did not hold staff to account: 'the management really did not want a problem. They wanted to just say the family was a problem, that the family were just making a lot of complaints, were overprotective. So that was from the top down. So nothing changed'
- **130.** In a similar case, the NDIS Quality and Safeguards Commission:

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⁴⁶ DRC Submission ISS.001.00072_0001, AMIDA response to the Group Homes Issues paper; 'Cases can be protracted as service providers drag out matters and respond inadequately'.

'took a lot of time to progress the complaint'⁴⁷. The advocate reported, 'They said it multiple times, "what do you want us to do about it?" and I said, "I want you to investigate it properly". So that's honestly how they were talking to me'.

- **131.** And, in this case, things worsened for the client who subsequently ended up in hospital. There are significant laws around the notion of 'danger to self and others' in mental health and in restrictive practice legislation. Yet when a person with a disability is potentially at such risk, similar, immediate measures are not taken to protect them in situations where others are a danger to them. DAV submits that this is an example of the general discrimination against people with disabilities, in that their safety, when pitted against service provider inconvenience, is not a priority.
- 132. However, there are some more deep-seated problems. For example, one young man was living in a forensic setting, subject to a supervised treatment order (STO). The STO was then not renewed, but his situation was never changed. There was an unspoken assumption that this person was a "permanent risk" for whom nothing more could be done. This assumption meant that the person continued to live in a high-security setting and no attempts were made to build his connection to family or community. At the same time, no "step downs" (graduated reductions in restrictions, in response to meeting goals of improvement in behaviours) were being applied and no work was being done with behavioural specialists to use positive behaviour support and introduce replacement behaviour strategies. Since his order had expired, all restrictions were now unauthorised. As a result, the person no longer had protection under the Victorian Senior Practitioner – Disability. The Senior Practitioner is responsible for ensuring the rights of persons who are subject to restrictive interventions and compulsory treatment are protected and that appropriate standards in relation to restrictive interventions and compulsory treatment are complied with. In such cases as this young man's, it is assumed that nothing more can be done.
- 133. The disability advocate had, first, to pursue the case at the state level with the Victorian Senior Practitioner and, subsequently with the NDIS Quality and Safeguards Commission. When the Victorian Senior Practitioner (VSP) informed the advocate they did not have a statutory duty in the case, the disability advocate contacted the NDIS Quality and Safeguards Commission (QSC). The QSC spoke with the VSP and neither seemed willing to respond to the disability advocate's enquiries. The young man was left incarcerated without protection during this period and, was it not for exceptional service from psychologists, occupational therapists and others, would have suffered more as a result of his detention.

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⁴⁷ DRC Submission Response to Issues Paper on Group Homes Queensland Advocacy Inc ISS.001.00216_01_0001 point to the ongoing problem with the speed of response from the Quality and Safeguards Commission, 'Only 47 per cent of 1,422 complaints received by the Q & S C were handled within six weeks of lodgement and a further 50 per cent were handled within six months. Others took more than six months. The report does not indicate whether those complaints were resolved —just handled', (p.13).

- 134. This case study highlights some extremely problematic processes. The QSC sought conversations with the VSP but did not keep the advocate informed despite it being a NDIS standard relating to complaints and incidents that all parties are kept informed. The QSC can be seen as acting as a 'judge and jury'. It did not collect the evidence from all parties. And even if the decision was correct the actions appear partisan. Further, regardless of whether the VSP had statutory authority in this case, there was still a victim whose life was being affected by the decisions being taken.
- **135.** The communication with services concerning a case by these authorities can also be an issue. One consultation participant said of this that,

'The service providers hold the narrative with the Quality and Safeguards Commission and with the service providers. [In this case] they seemed unwilling to respond to the family. They see families as making complaints or being disruptive'.

and Safeguards Commission are opaque and their capacity to respond sufficiently quickly is an issue. As it is part of the NDIS it is also seen as a part of that 'service system'. The movement of these regulatory procedures to a national body such as the QSC takes the process one step further away from Victoria.

Barriers to Accessing and Achieving Justice

- 137. Our case studies show that the struggle to achieve justice is often long and complex. The process can require energy which is often beyond the means of the victim to pursue without support. In many cases people with disability have limited or no knowledge of the justice system due to a failure to be educated, and the physical, procedural, and structural barriers in court processes and structure makes it difficult for them to engage.
- **138.** In a majority of case studies, it was surprising to note that the accepted channels for complaints had either been exhausted or resistant, leading to extreme measures having to be taken. These included lodging complaints with government departments, elected members, the Ombudsman and others. The following are some of the examples:

'The client was referred by the Office of the Public Advocate for individual advocacy in her housing situation. She was living in community housing in Victoria where she was the victim of extreme racial hatred from a neighbour. The client believed her neighbour was trying to force her to leave and took out an intervention order against the neighbour to prevent her from coming onto her property. The bullying behaviour was reported to the community housing provider; however, no further action could be taken to prevent the neighbour from continuing with bullying other than the client moving residence.

The advocate assisted the client by writing to the Office of Housing, the Victorian Housing Register, the NDIA, the state minister for Housing, the state and federal ministers for Disability and the client's local Member of Parliament.

Within two weeks the advocate received communication from the local Office of Housing to discuss a housing transfer. Within a month the client was offered a transfer to a high-density public housing block, but this was declined as she was not able to live in a high-density setting. Within another three months, the client was made another offer for low-density housing which she accepted. The advocate argued for the client to be exempt from some of the eligibility restrictions due to her medical condition and disability, supported by evidence from the client's treating practitioners'.

'A client with an intellectual disability was charged by the police following an alleged incident with a minor. Victoria Police attended the client's home for "a chat", and then with no legal representative or independent third party he was taken back to the local police station and charged. The client had no awareness of the criminal justice system and the family sought advocacy assistance to understand their son's rights in this circumstance. The advocate contacted a criminal lawyer who was prepared to take on the case pro bono, provided that the advocate remained involved to support the client. At the family's request, the advocate engaged a forensic psychologist to determine the client's capacity to stand trial. The advocate found the local police difficult to engage with as they appeared to have little understanding of the client's disability and his limited comprehension of the criminal charges'.

139. These and many similar cases reported show that achieving justice for people with disability often require rigorous advocacy before anything is done⁴⁸. This raises several concerns about the current system and processes; if the threshold for achieving justice is set this high, the systems presently in place are not working sufficiently well.

Length and complexity of the complaints process

- **140.** The DAV case study survey found that, in 78% of cases, several elements collectively contributed to violence and abuse while, in 64% of cases, the complexity of the case meant it was hard to resolve quickly. (Appendix 2)
- **141.** The time required either for a response or to ensure procedural fairness, can lead to the situation deteriorating further. For example, in one case the NDIS Quality and Safeguards Commission (QSC) took so long to respond to a case that the circumstances had come to a head while the advocate was awaiting a response. In this case,
 - '... when additional complaints were lodged they [QSC] closed the previous case, because things had escalated and now it was a police matter'.

⁴⁸ DRC Submission, Group Homes Issues Paper, Queensland Advocacy Inc ISS.001.00216_01_0001 make a similar point as follows, 'If the survivors of crimes reported in the media, and discussed as examples at the Housing Public Hearing, still did not receive independent supports and services after such exposure, we can only imagine the trauma and harm occasioned upon anonymous people in every and each group home across Australia', (p.18). The level at which evidence is often required is referenced also in, DRC Submission to the Education Issues Paper, Autism, Asperger's Advocacy Australia,

ISS.001.00054_01-0028. They point to the fact that the 'child is blamed and parents accused of lying unless clear pictures or video of evidence is made public' (p.31).

142. This waiting time can be extended in other ways as well:

I emailed them [statutory authority], tried to do mediation, asking how to get this going and what steps we need to take and who we need to talk to reassure you about those steps...but they would not get back to me⁴⁹. They tried to stop me at many points to say "you're advocating for the family and not for [client name]" and I'd say "No. These are all his goals on his NDIS plan".

143. The complexity of some cases also meant that a number of people needed to be involved. In one case study relating to family violence and abuse, a significant amount of planning, careful implementation and coordination were required. The disability advocate describing the case said:

'Plans involved a multiple agency collaboration (disability advocacy, community legal representation, police, specialist disability family violence and abuse unit with family violence and abuse services and NDIS funded services) to be coordinated and in place. A collaborative approach was vital to maintaining the safety of the PWD. It required everyone on board within the limits of their respective roles. The need for the exit plan to be implemented in the correct order with services in place to provide support for the PWD: The logistical barriers were immense. This included PWD to attend the nearest VicPol station to report abuse and make a statement including the need for an ITP to attend police then to attend the home to remove the perpetrator, family violence and abuse services attend home together with a locksmith to secure property, support worker to have active overnight shifts until a new plan could be drawn up, attendance at IVO hearing for an ongoing protection order and VCAT Hearing for removal of the perpetrator as administrator. Phone calls to NDIA to remove perpetrator as NDIS nominee and to redirect funds to PWD's bank account. Physically attending banks with a copy of the Order to prevent the perpetrator from withdrawing cash assets from bank accounts before the new administrator (State Trustees) becomes actively involved...'

- **144.** The complex role played by disability advocates in seeking to uphold the rights of persons with disabilities is well demonstrated in the case studies. The key point is that many cases of violence and abuse involve numerous parties and a complex series of interactions across many domains, which need to be coordinated.
- 145. If anyone from amongst these organisations is resistant, raises procedural issues, or acts to deflect or protect their interests, the process can grind to a halt as demonstrated in several of the case studies discussed throughout this submission. Problems such as these with several people, processes, policies and regulations where there is no single person or group capable of or, indeed, having the authority, to coordinate the ongoing process, have a high degree of difficulty in terms of resolution.

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⁴⁹ The NDIS Effective Complaint Handling Guidelines state, 'If a person with disability affected by an issue raised in a complaint has a decision maker, advocate or substituted or informal decision maker, these people may need to be included and recognised in the complaints management and resolution process, depending on their role in the life of the person with disability' (p.9). It is therefore interesting that the Quality and Safeguarding Committee did not do so in this case.

- **146.** Additionally, it should also be noted that disability advocacy agencies are paid by the number of people with disabilities seen, and not by the hour, unlike other professionals. Complexity is not considered and this impacts their capacity to respond to demand.
- **147.** If it takes too long for complaints procedures to be completed, then the very system designed to promote, protect and ensure a person's rights becomes in and of itself, disempowering.

D4. Systemic Issues

- **148.** DAV suggests that behind much of what has been said above, there are issues with the very systems designed to promote, protect, and ensure the human rights of people with disability, and to prevent them from being subject to violence and abuse.
- **149.** The DRC academic papers so far written, the issues papers, and most importantly the DRC's Interim report, show a consistent theme that discrimination, intersectionality as well as context and situation, contribute to violence and abuse against people with disability.

'Exclusion occurs when people are denied access to the social, economic, political and cultural systems that enable a person to be part of the community. The segregation and social exclusion of people with disability produce stigma and discrimination, which may and has led to violence and abuse, abuse, neglect and exploitation'⁵⁰.

150. A range of systemic issues that exacerbate or cause violence, abuse or neglect of people with disability were raised in the consultations. These included:

Economic, social and cultural rights

rights such as housing, education, and employment which were contributing to violence and abuse. It has already been said that if people could escape violence and abuse they would choose to do so. We know the same issues about escaping violence and abuse have been raised and recognised in the family violence, and abuse reform, addressing the complex issues victims have to navigate. The family policy creates a raft of solutions from changing public attitudes to places of safety, supporting women to make complaints safely and establish and make the case. The policies have also invested in the workforce and its training⁵¹.

⁵⁰ Commonwealth of Australia (2020) Interim Report: Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, Barton: Attorney-General's Department. October 2020.

⁵¹ DRC Submission, Women with disabilities Australia, ISS.001.00242_0002 talk in this respect about the need 'Australian governments should develop nationally consistent legislation on the prevention of all forms of gender-based violence abuse for all women and girls that reflects the definition of 'gender-based violence and abuse' outlined in the Committee on the Elimination of All Forms of Discrimination Against Women (CEDAW) General Recommendation 35 'Gender-based Violence and abuse Against Women' (2017)' (p.5, para 1.15).

- **152.** Looking at data about why people with disability are not able to escape violence and abuse, we found that the lack of resources to do so is the biggest issue. We also found that despite the NDIS, choice and control can be impossible given the way disability policy and service systems operate.
- **153.** A further complication with housing, education and employment rights is that they are subject to progressive realisation. Unlike civil and political rights in which an infringement of rights can be identified, economic, social and cultural (ESC) rights are dependent upon how much funding government provides for people to make their choices in these areas. This means improving these rights will remain dependent on resources that are made available.
- **154.** For states, parties and signatories to the CRPD to meet the requirements relating to economic, social and cultural rights requires them to show this slow change or progressive realisation over time. Because of this, the exhortation of the government to improve these rights through the injection of significant new resources will take time.
- **155.** The following examples from our data relating to accommodation exemplify how this can play out in the lives of people with disability subject to violence and abuse.
- **156.** In a situation in which the person's safety was at risk unless alternative housing was provided, the person was,
 - '...unable to get priority housing...due to long waitlists and systemic issues. They are both ineligible for housing support due to having current accommodation, despite it being unsafe and unliveable...He is ineligible for many disability supports due to not having enough documentation relating to his diagnoses as a result of not receiving appropriate care'.

Similarly

- '...for a person who was intimidated because of the smell of food in a boarding house 'NDIS wouldn't provide emergency accommodation and the client would only pay a set amount for rent as they were supporting a minor overseas where there was no welfare system'.
- 157. Considering the evidence presented above, DAV believes that social and emergency housing must be provided for people with disabilities if they wish to immediately escape violence and abuse in their home (Recommendation 13). There is a clear need for increased funding to address the lack of housing options available to people with disability facing violence and abuse.

Attitudes

158. DAV agrees with the DRC that deep-seated attitudes to people with disability can have a huge and significant impact. For example, ableist thinking and discrimination in its many forms can have a huge negative impact where micro-aggressions and low-level bullying, or consequence control, can be used prolifically but not recognised as a problem. Not accepting and acting upon people's complaints because of their disability offers one example of this. The DAV case study survey

found that in 91% of cases there was a 'Perception by others (discrimination, ableist thinking, stigma) [that meant] the person's rights are not recognised and actions taken' (Appendix 2).

Service Gaps

159. There are further examples of how siloed systems allow some people to fall through the service gaps and, then become more vulnerable. For example in two cases a gap between the ages of 16 and 18 limited the options of the young people concerned:

'...young man 17, too old for Early Childhood Early Intervention, and Child protection – had no access to NDIS'

160. In a similar case,

'A 17-year-old client's parent was constantly drug-affected and not supporting him. His legal guardian was his grandparent who was also the manager of his NDIS plan. The grandparent was now out of the picture and uncontactable. This meant the client was unable to access any funded support, was facing homelessness, had no income, was malnourished, and was experiencing a mental health crisis. Child Protection services could not assist him as he was older than 16, and other services and supports were not available to him since he was not 18. Being under 18 meant that he could not access and manage his NDIS plan'.

161. In another case,

'The client has a funding package but the service provider withdrew due to a pest infestation in his home. They did not implement any recommendations from a neuropsychological assessment they had used his funding to obtain'

- **162.** In relation to this case, the consultation participant suggested that 'He fell through the gaps and many services were unable to provide him with adequate support. There was not enough knowledge of his needs and rights'.
- **163.** It is critical that the service systems provide a coordinated continuum of support to people with disability to manage risks of violence and abuse and address safety concerns and disability support needs. If the service systems do not provide a coordinated response, the risk of violence and harm to people with disabilities is increased.

Legislation and policies

164. The DAV consultation also asked about limitations of legislation and policy in relation to violence and abuse, particularly in the focus group which was held with leaders of the Victorian disability advocacy sector. A participant summarised the current lack of sufficient legislation as:

'They [laws and policies] help but they are not sufficient. We need laws and policies that are easily understood and interpreted and are straightforward'

165. Furthermore, we found examples in which people with disability are discriminated against on a day-to-day basis, but the disability discrimination protections are insufficient. As one focus group participant put it:

'Like I said, policies and law are very confusing because most people and organisations would like to interpret it as it suits them... Our society is built on being the most productive, rather than the most inclusive. This is reflected in the built environment, as well as in businesses and the private sector generally. People with disability are often excluded as a result'.

- **166.** Further, the system of accessing legal help is also fraught, 'The tackling of disability discrimination through the legal system has made it a clear barrier for people with a disability in seeking redress and so this option is sparingly used'.
- **167.** Another reflection on what contributes to violence and abuse points to the 'Threat of costs if you use the Disability Discrimination Act. Not enough funding for Lawyers to use the Disability Discrimination Act'
- **168.** For example, the Disability Discrimination Legal Service in Victoria has a base staffing of 2.7 EFT responsible for assisting people with disabilities throughout Victoria with disability discrimination cases⁵².
- **169.** Some people with disabilities, particularly school children, use discrimination legislation for complaints about restrictive practices in the face of no appropriate alternative legislation.

D5. Family Violence and Complaints

- **170.** Families can also subject people with disabilities to violence and abuse, and at times the dynamics between families and service providers together pose more of a barrier to people attempting to have such violence and abuse addressed.
- 171. In the survey of disability advocacy groups, one participant pointed to the fact that issues around violence and abuse by family members were some of the most complex cases. There were reports of the time it could take to establish sufficient relationships with a family to be able to raise an issue. There was always a danger family could withdraw their relative from services if they felt threatened or disrespected. This meant the person and the person's experience of violence might continue behind closed doors.
- 172. In one such case, there was a suspicion of neglect and financial abuse by a parent:

 A disability support worker contacted an advocate to assist with an identified issue of neglect and exploitation for a 40-year-old man who attended a day program service. The support worker knew that the client (who has significant intellectual disability) lived at home with a parent who spent the client's money

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⁵² This point relating to limited access to legal services has also been recognised in the DRC Interim report, 'We have also been told that people with disability face difficulties in accessing legal assistance or advice' (p. 380).

and had no legal authority to do so. The client's mother would not buy clothes or shoes for her son and the son often smelled of urine, indicating an incontinence issue that the mother would not address. The support worker was very concerned for the welfare of the client and sought advocacy to assist with his human rights in the circumstances.

173. In the example discussed above, although the disability advocate had already become involved and had spent a lot of time with the family building trust to engage them, the manager of the disability service pointed out that no Incident Forms had been completed by their staff member (the support worker). The manager argued that there was no evidence, using the lack of an incident report⁵³, as evidence that the threshold to escalate the issue had not been reached. In the context of the advocate's continued contact and claims, the manager eventually contacted the advocate,

...to tell me the situation was not neglect or exploitation, of which I argued it was'.

'This was concerning that the service provider was unclear about what constituted neglect or exploitation of a person with a disability. Even after the support service had completed the mandatory quality and safeguards training, the management did not recognise this as a breach of the client's human rights'.

- **174.** This situation raises the issue of when 'an incident' has occurred and when further investigation is warranted⁵⁴. It also raises the issue of who has the power to define such situations and to make a judgement about whether that situation meets the threshold at which the case should be taken further.
- 175. In this case, it was the service manager who held this authority. Under the NDIS Code of Conduct, every service provider must have a Complaints Procedure and 'anyone can make a complaint'. The manager used the lack of an Incident Report, which has to be submitted to the Quality and Safeguards Commission, as a proof that issue didn't need any further action. Yet the organisation should still have applied the complaints procedure. The authority of the manager in this case to address the complaint internally points to issues with self-regulation and why it cannot and does not work sufficiently or comprehensively.
- **176.** Once the manager's decision was given, the advocate was left with the question of whether to address this with the family and without the support worker who had referred the issue in the first place. As already stated, the issues with the family

⁵³ The gap between incidents and complaints is large. In the Reportable Incidents: Detailed Guidance for Registered NDIS Providers (June 2019) there is a list of reportable incidents on page 5 into which this case would not fit. Then on page 21 there is a definition of "grossly inadequate care" which refers to a registered NDIS provider depriving a person with disability of the basic necessities of life, such as food, drink, shelter, medical care or clothing'. It is not clear this case meets the criteria for an incident but it does meet the grounds for a complaint.

⁵⁴ Under the NDIS Act 2013 'abuse and neglect' 'sexual and physical contact' and 'sexual misconduct' are reportable incidents (see NDIS Code of Conduct Para. 72). For cases that come to NDIS registered services, once it is a case it must be reported to the Quality and Safeguards Commission. Since this is self-regulated at the service level, there is room for resistance in accepting a verbal complaint as an 'incident'. Examples of this have already been submitted to the DRC. See DRC submission 0080.0001.0001, New South Wales Ombudsman.

were challenging and there was a fear they would withdraw their relative from services and raise barriers if challenged⁵⁵.

- 177. These are very real concerns for advocacy agencies. There is often constant juggling regarding the actions the agency believes need to be taken to minimise harm, but on the other hand, ensuring a person's family members are "on the side" to continue to be able to access the person with a disability. Decision-making is often impacted by this balancing act involving those with legal and nonlegal authority over the person with a disability, in order to avoid disengagement with advocacy and resulting in isolation and possible continuation of violence and abuse.
- 178. Where power resides so much with one resistant party, this can prevent a complaint from moving forward by using their service systems procedures. This is a worst-case scenario as many services will follow up on such complaints. However, case study survey participants reported these circumstances happening in many cases. This situation is illustrated by a statement regarding services made by one consultation participant:

'Services are concerned with the organization's public image rather than tackling head-on any abuse that has been brought to their attention'.

E. The role of individual and systemic advocacy in change-making

- **179.** The DAV consultation and specific cases discussed in this document provide detailed insight and evidence around the ways in which disability advocacy plays a central role in the lives of people with disability, specifically in relation to addressing violence and abuse.
- **180.** Reflections and case studies shared by the disability advocates across Victoria show that mainstream and disability services are not always inclusive of people with disability and advocates work with people with disability, their families and carers to identify and work through particular barriers as they are presented by the services and the system. Advocates build relationships with a range of people in key roles in the system in order to help people with disability navigate the very systems designed to promote and protect their rights, and to prevent them from being subject to violence and abuse.
- **181.** Australia's Disability Strategy 2021-2031⁵⁶ also highlights the importance of disability advocacy and its significant role in assisting people with disability in ways which relate to all of the Outcome Areas of the Strategy and in identifying service gaps and issues in quality of support provided to people with disability that constrain their participation.

⁵⁵ In this submission we have not sufficiently addressed issues for people who live in families but who do not access services. This group is the hardest to reach in terms of policies around addressing violence and abuse.

⁵⁶ Commonwealth of Australia (2021), Australia's Disability Strategy 2021-2031, https://www.disabilitygateway.gov.au/document/3106.

- **182.** The findings from the consultation also point to the growing role and demand for disability advocacy with more people with disability seeking advocacy services to help them navigate the systems and services. This places significant pressure on the sector where demand for advocacy is outstripping the capacity to respond. With already limited resources at their disposal, disability advocacy organisations are forced to limit access to their service, and this impacts on their capacity to assist those reporting violence and abuse.
- **183.** State of the Disability Sector Report 2020 shows that service providers are concerned about the lack of access to advocacy and around 65 percent believe that there is insufficient advocacy for the people they support⁵⁷.
- 184. Much of this increased demand is also attributable to the NDIS. The full roll-out of NDIS has transformed the service landscape for people with disability. Advocating for people experiencing difficulty with the NDIS was a significant change for many disability organisations from what was previously their core work with the mainstream system. Difficulties people with disability have with the NDIS takes considerable effort and resources of the advocacy sector, and now a significant part of their work has become supporting people to access and navigate the NDIS. Although the NDIS is relevant to just 10 per cent of the population of people with disability⁵⁸, it has become the largest area of work for advocacy and information organisations. This is often attributed to the complexity of NDIS that many people with disability are attempting to navigate. An unprecedented increase⁵⁹ in NDIS appeals over the past few years has resulted in crisis advocacy, taking any focus away from prevention and early intervention.
- **185.** The pandemic and the subsequent recovery period created additional challenges for people with disability, adding to the demand for advocacy. The challenges range from social isolation, financial crisis, struggle with use of technology, withdrawal of or changed access to existing services, mask wearing created additional communication barriers for Deaf & hard of hearing people, and the impact of social distancing measures and physical isolation laws on the support provided by family, community, and services. According to DANA Snapshot Survey of COVID-19 Impacts in 2020, 42% of advocacy organisations stated that they were unable to meet the increase in demand for advocacy services during this period⁶⁰.
- **186.** The DAV consultation also found a clear link between the lack of investment in advocacy and the growing role they play in this space. In the focus group, participants reported that systemic advocacy was too poorly funded to contribute to ongoing calls for changes to systems, policies, regulations and laws. Generally, in

⁵⁷ National Disability Services (NDS), State of the Disability Sector Report 2020, pg. 24 https://www.nds.org.au/about/state-of-the-disability-sector-report

⁵⁸ Productivity Commission 2017, National Disability Insurance Scheme (NDIS) Costs, Study Report, Canberra. p.g.3-4

⁵⁹ Henriques-Gomes, L., 2021. "Legal challenges against NDIA decisions more than triple in five months' *The Guardian:* Australia Edition https://www.theguardian.com/australia-news/2021/dec/11/legal-challenges-against-ndia-decisions-more-than-triple-in-five-months

⁶⁰ Bennett, P., 2020. DANA Snapshot of COVID-19 Advocacy Demand. Disability Advocacy Network Australia (DANA). https://www.dana.org.au/wp-content/uploads/2020/06/DANA-COVID-19-Snapshot-Report-FINAL.pdf p.g. 5.

Victoria, organisations funded to provide systemic advocacy have to "choose their battles". Findings revealed that one organisation with a focus on women is trying to walk a tightrope between the disability reform agenda and the family violence and abuse agenda, both of which have been subject to the significant change in recent years.

187. At present systemic advocacy organisations do not feel sufficiently represented in the disability sector policy discussions as well as across other policy domains such as family violence and abuse, health, refugees and asylum-seekers, LGBTQIA+, as well as CALD policy arenas to have the greatest impact in relation to the rights of people with disability across administrative boundaries.

'Think how amazing it would be for all of us to be around the table with senior policy people including representatives from the Minister's office to actually hear what's happening on the ground. That seems to be a key missing point for advocacy organisations in the sector to advocate for change'!

- **188.** Given the central role of advocacy, highlighted throughout this submission, DAV maintains that it needs to be recognised accordingly and funded appropriately (Recommendation 14). Developing and supporting advocacy mechanisms that empower individuals to be meaningfully involved in decision-making will eventually lead to creating policy and strategy that is meaningful for people with disability.
- **189.** A strong argument can be made that without a well-resourced disability advocacy sector, violence and abuse against people with disability will exacerbate. When disability advocates have high demand from the disability community and limited capacity to respond, it is self-evident that some, or many, individuals will not be assisted. A strong and well-resourced advocacy sector will not only bridge the service gap left by the siloed systems but will also make an important contribution to abuse prevention.
- **190.** The significance and role of self-advocacy in policy reform, service review and development, and safeguarding the rights of people with disability is very relevant in the context of violence, abuse, neglect and exploitation. For instance, self-advocacy training can play an important role in assisting people with disability to identify abuse and inappropriate behaviour⁶¹.
- **191.** The capacity building, advisory and co-design work undertaken by self-advocacy groups and the organisations supporting them, often extends beyond individual needs to considerable systemic advocacy for the needs of those in the group and others with similar experiences. Building personal capacity to self-advocate goes beyond strengthening individual safety.

'Self-advocacy groups provide opportunities for social and civic participation of people with intellectual disability benefiting both individuals by building identity

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⁶¹ 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, 196.

and social networks but also increasing their visibility in the community as citizens playing valued roles, contributing to changed social attitudes'62.

- 192. However, the availability of self-advocacy services is limited and the opportunities and significance of self-advocacy is often overlooked and undervalued with available funding that has largely been project-specific and short-term. DAV would like to see government commitment to increased funding for self-advocacy groups, given their effectiveness in building social and support networks, to address isolation to assist in training people with disability about human rights, speaking up and advocacy (Recommendation 15).
- 193. DAV strongly supports the role of advocacy in the Australia's Disability Strategy through the interface with National Disability Advocacy Programme and State funded advocacy. It is important to ensure both the individual and collective voice of people with disability is elevated and that services and system are continually challenged to improve through constructive and independent feedback. The feedback for continuous improvement and issues raised at systemic level through advocacy—in all its forms, individual, systemic and self—will ultimately reduce the need for corrective measures through better resourced and more effective mechanisms and supports for people with disability, ensuring the human rights of people with disability, and safeguarding them from being subject to violence and abuse.

F. Conclusion

- 194. People with disability experience different life opportunities from people without disability due to people with disabilities not being provided necessary resources they need to access opportunities. This experience of everyday discrimination and the mistreatment of people with disabilities in Australia is prolific and requires urgent attention. The financial and human cost of violence and abuse is very high, and often long term in relation to addressing trauma and health care needs, and the impacts are not limited to people with disabilities, but also their families, the communities they identify with, and society overall. Disability advocates mentioned during the consultation that they experienced a deep emotional impact from cases and recognised that these feelings extended to those people employed within disability services. Vicarious and secondary trauma such as this also carries significant costs over time.
- 195. Based on the evidence and case studies, this submission establishes that advocacy is a critical safeguard that directly focuses on abuse and neglect and protect the rights of people with disability. Drawing substantively on the views of people with disability subject to violence and abuse, advocates and disability advocacy sector, DAV seeks to address the specific questions set out in the DRC's Letters Patent in relation to the barriers to reporting, investigating, and effective responses to address violence and abuse, specifically in the context of advocacy.

⁶²Bigby, C. (2015) *Self-Advocacy and Inclusion – A Summary of the Study 'What can be Learned from Speaking Up over the Years?'* Living with Disability Research Centre, La Trobe University, Victoria, p8.

- 196. In using case studies to address the DRC's terms of reference, we have highlighted a number of issues reflecting problems with services, systems and legislation.

 Throughout the submission we provide recommendations that point to ways of ensuring people with disabilities facing violence and abuse are 'visible' to services, systems and government, and to address the structural and systemic barriers that restrict and/or prevent them from accessing support, advocacy, and safety.
- 197. We believe that if disability advocacy is to address violence and abuse it will require adequate resources and funding to do so effectively. Continued attention needs to be paid to the gaps at the interface between different service systems and the role of advocacy. Giving voice to people with disability experiencing disadvantage across these service systems and gaps, must be recognised and supported by the Commonwealth government. Our consultation also asked disability advocates to suggest practical solutions to violence and abuse, the results of which are summarised in Appendix 5. While some of the suggested solutions may not transfer to a Commonwealth framework, we maintain they are useful to consider given they emanate from those that work in the field.

Appendix 1 – DAV Inc Case studies

A survey question before each case study asked whether the case involved violence, abuse, neglect or exploitation. More than one choice could be made explaining why the responses in the right-hand column add up to over 22. The table below shows the responses to this question.

Table showing the focus of case studies concerning violence, abuse, neglect and exploitation.

ANSWER CHOICES	RESPONSES
Violence	17.39 (4)
Abuse	69.57 (16)
Neglect	60.87 (14)
Exploitation	26.09 (6)
Total Respondents: 22	

Appendix 2 – Factors identified as contributing to violence, related to DAV Inc case studies.

Factors identified as contributing to the VANE	Yes % (n)	No	Not sure
Perception of others (discrimination, negative attitudes, ableist thinking, stigma) means the person's rights are not recognised and actions are taken.	91 (21)	9(2)	
Limited or no community support networks	82 (18)	14 (3)	5 (1)
Confusion amongst service staff about what a human right is in practice	78 (18)	13 (3)	8.7 (2)
The person with a disability speaks up but is ignored	74 (17)		26(6)
No supported decision-making has taken place	70(16)	26 (6)	4 (1)
Isolated from other supports and a confidente capable of responding to the issues	65 (15)	22 (5)	13 (3)
Inadequate services and oversights – lack of funding	70 (16)	9 (2)	22(5)
The person with a disability is frightened to speak up	61(14)	26(6)	13(3)
The person with a disability stated that they felt 'resigned to their fate'	61 (14)	35 (8)	4 (1)
Lack of focus on everyday rights by services (e.g. access to a toilet, drinking, clean clothes etc)	73 (16)	14 (3)	14 (3)
Use of informal and non-recordable restrictions to control the person	70 (16)	26 (6)	4 (1)
The person with a disability lacks information and knowledge about human rights or the process to make a complaint	78(18)	17(4)	4(1)
Services using informal procedures to address an issue or promising to do so, and not following up	68 (15)	18 (4)	14 (3)
Lack of individual plans and supports to achieve the person's goals	65 (15)	17 (4)	17 (4)
The person with a disability is seen as an unreliable witness	68(15)	18(4)	14(3)
The person with a disability is subject to low-level bullying, harassment, and verbal warnings	65 (15)	35 (8)	
Having few family and friends contributed to the violence, abuse, neglect and/or exploitation	65 (15)	17 (4)	17 (4)
Power is in the hands of just one service provider or worker	57 (13)	30 (7)	13 (3)

Several causes came together in this case to create the violence, abuse, neglect or exploitation?	78 (18)	9 (2)	13 (3)
There is a greater likelihood of violence, abuse, neglect and/or exploitation for this person because of age, gender, cultural identity,	70 (16)	26 (6)	4 (1)
The complexity, in this case, meant that it was difficult to resolve quickly?	64 (14)	32 (7)	5 (1)
The person with a disability has no contact or means of contact with advocacy organisations	55 (12)	32 (7)	14 (3)
(Inability of the person with a disability to speak up. No choice or control means they did not know they could speak up)	59 (13)	27 (6)	14 (3)
There was a culture within the service that was likely to lead to violence, abuse, neglect or exploitation?	36 (8)	41 (9)	23 (5)
Staff are frightened to speak up	43 (10)	22 (5)	35(8)
Staff conflict of interest	26 (6)	48 (11)	26 (6)
Congregate care settings contributed to violence, abuse, neglect or exploitation	44 (10)	35 (8)	22 (5)
The person with a disability is subject to formal reportable restrictive practices	39 (9)	52 (12)	9 (2)

Appendix 3 - DAV Inc Consultation – Identified solutions designed to address violence and abuse

Solutions designed to address VANE	Strongly agree	agree	Neither agree/ disagree	disagree	Strongly disagree
Disability advocates helping reduce the formality and complexity of service, legal and other systems	87.5 (21)	12.5 (3)			
An expanded supported decision making role	92 (22)	8 (2)			
Supporting people with disability to navigate systems (health, education work etc)	87.5 (21)	8 (2)	4 (1)		
Increased funding for disability advocacy groups	92 (22)	8 (2)			
Introducing disability advocacy outreach services	87.5 (21)	8 (2)	4 (1)		
Greater rights of access for disability advocacy organisations to disability services	87.5 (21)	12.5 (3)			
Use of self-advocates as trainers in services and communities	83 (20)	4 (1)	8 (2)	4 (1)	
More accessible information for people with disability	79 (19)	21 (5)			
Funding that recognises the complexity of disability advocacy cases	92 (22)	4 (1)			4 (1)
Maintaining the independence of disability advocates	96 (23)	4 (1)			
Embedding people with disabilities and self-advocates in services for awareness-raising (police, courts, schools etc)	87.5 (21)	12.5 (3)			
Reducing complex bureaucratic form-filling	83 (20)	12.5 (3)	4 (1)		
Getting rid of 'toothless' policies around safety,	87.5 (21)	12.5 (3)			

protection, quality and safeguarding					
'Sensitive systems' and early intervention prompt visibility and draw in advocacy	75 (18)	25 (6)			
Self-advocates have communities of practice to build their capabilities	75 (18)	17 (4)	8 (2)		
Increasing the role of self- advocates in networking and safeguarding practices	75 (18)	21 (5)	4 (1)		
No one disability service has a sole or majority "ownership" of our engagement with the person with a disability	79 (19)	17 (4)	4 (1)		
Intermediary or third person schemes in which advocates support people to speak for themselves	75 (18)	21 (5)	4 (1)		
More statistics about violence, abuse, neglect and exploitation	62.5 (15)	29 (7)	4 (1)	4 (1)	
A greater role for systemic advocacy	75 (18)	17 (4)	4 (1)	4 (1)	
Less adversarial settings (courts, tribunals etc)	52 (13)	29 (7)	17 (4)		

Appendix 4 – DAV Inc Consultation – survey results relating to self-advocacy

auvocacy						
	Strongly agree	agree	Neither agrees/ disagree	disagree	Strongly disagree	Don't know
Self-advocates are largely not paid for their role and give their time for free	63 (12)	21 (4)	5 (1)			11 (2)
Self-advocates talk to a wide range of people with disabilities about their rights	42 (8)	21 (4)	5 (1)	16 (3)	5 (1)	11 (2)
Self-advocates talk to people with disability about their living situation and day services	37 (7)	42 (8)	11 (2)		5 (1)	5 (1)
Self-advocates support people to speak up and be confident	56 (10)	28 (5)	11 (2)	6 (1)		
Self-advocates run peer to peer, support groups,	67 (12)	17 (3)	17 (3)			
Self-advocates build new networks with people with disability over time	56 (10)	22 (4)	17 (3)			6 (1)
Self advocates educate the general community about people with disability	50 (9)	17 (3)	11 (2)	6 (1)	6 (1)	11 (2)
Self-advocates produce resources that can be used by people with disability	56 (10	28 (5)	11 (2)	6 (1)		
Self advocates give people information about local community services they can use	50 (9)	28 (5)	6 (1)	6 (1)	6 (1)	6 (1)
Self-advocates are involved in projects around the rights of people with disability	61 (11)	28 (5)	6 (1)	6 (1)		
Self-advocates have sufficient representation on government and community committees		12 (2)	12 (2)	29 (5)	47 (8)	
Self-advocates campaign for the rights of people with disability	61 (11)	33 (6)		6 (1)		

Self-advocates help apply for funding for projects to support the rights of people with disability	22 (4)	56 (10)	6 (1)		17 (3)
Overall there are sufficient funds for self-advocates to protect the rights of people with disability in our community.		5 (1)	42 (8)	53 (10)	

Appendix 5 – Disability advocacy solutions across different areas of focus.

Table – Advocacy solutions across differing areas of focus

	Areas of	Solution	Percentage who
	Focus		'strongly agree'
1	Community	Self-advocates have communities of practice to build their capabilities	81%
2	Changes at the systemic	Use of self-advocates as trainers in services and communities	90%
3	level	Embedding people with disabilities and self- advocates in services for awareness-raising (police, courts, schools etc)	90%
4		Reducing complex bureaucratic form-filling	90%
5		Increasing the role of self-advocates in networking and safeguarding practices	81%
6		No one disability service has a sole or majority "ownership" of our engagement with the person with a disability	73%
7		A greater role for systemic advocacy	64%
8		Less adversarial settings (courts, tribunals etc)	55%
9	Early intervention	Greater rights of access for disability advocacy organisations to disability services	90%
10		Introducing disability advocacy outreach services	90%
11		Intermediary or third person schemes in which advocates support people to speak for themselves	72%
12		Sensitive systems and early intervention prompt visibility and draw in advocacy	82%
13	Having a voice	An expanded supported decision-making role	100%
14		Disability advocates help reduce the formality and complexity of service, legal and other systems	100%
15		Supporting people with disability to navigate systems (health, education work etc)	100%
16		More accessible information for people with disability	91%
17		Getting rid of 'toothless' policies around safety, protection, quality and safeguarding	90%