



Submission to the Senate Inquiry into violence,
abuse and neglect against people with disability in
institutional and residential settings

Advocacy for Inclusion

June 2015

**About Advocacy for Inclusion
Home of the Disability Rights Law Centre**

Advocacy for Inclusion acknowledges the Ngunnawal people as the traditional owners of the land on which we work.

Advocacy for Inclusion provides individual, self and systemic advocacy services for people with disabilities. We provide information, education, and representation to effectively advocate for positive and inclusive outcomes for people with disabilities.

We act with and on behalf of individuals in a supportive manner, or assist individuals to act on their own behalf, to obtain a fair and just outcome for the individual concerned.

Advocacy for Inclusion works within a human rights framework and acknowledges the *United Nations Convention on the Rights of Persons with Disabilities*, and is signed onto the *ACT Human Rights Act*.

Contact details:

2.02 Griffin Centre
20 Genge Street
Canberra City ACT 2601

Phone: 6257 4005

Fax: 6257 4006

Email: info@advocacyforinclusion.org

ABN: 90 670 934 099

General Manager: Christina Ryan

Policy Officer: Ellen Read

This submission was made possible with assistance from Disability ACT and the Commonwealth Department of Social Services.

June 2015

(c) Copyright Advocacy for Inclusion Incorporated

This publication is copyright, apart from use by those agencies for which it has been produced. Non-profit associations and groups have permission to reproduce part of this publication as long as the original meaning is retained and proper credit is given to Advocacy for Inclusion Inc. All other individuals and agencies seeking to reproduce material from this publication should obtain the permission of the General Manager of Advocacy for Inclusion.

Table of contents

Recommendations.....	4
Introduction.....	6
Hearing people with disabilities	7
The status of people with disabilities.....	8
Deinstitutionalisation: unfinished business	10
Power dynamic in institutional settings: a recipe for violence	11
Direct personal stories of violence, abuse and neglect.....	22
Systemic workforce issues	27
Solutions: preventing and responding to violence against people with disabilities	30
Conclusion	36

Recommendations

Recommendation 1: Hold a Royal Commission into violence, abuse and neglect against people with disabilities in institutional settings.

Recommendation 2: As per international obligations and recommendations by UN treaty monitoring bodies, the Commonwealth should fund an ongoing comprehensive assessment of the situation of children and adults with disabilities to establish a baseline of disaggregated data against which compliance with UN treaties data collection on people with disabilities can be measured across the full range of UN treaty obligations.

Recommendation 3: Institutional models of support for people with disabilities are inherently flawed and must be defunded and phased out. The Commonwealth should establish a national plan for the full deinstitutionalisation of people with disabilities.

Recommendation 4: Commit to a properly resourced *National Disability Strategy* and through that support the genuine inclusion and deinstitutionalisation of people with disabilities, and implementation of the *Convention on the Rights of Persons with Disabilities*.

Recommendation 5: Commonwealth to fund support for people with disabilities to have real jobs for real pay. Sheltered workshops must be phased out with funds diverted toward creating access and support in mainstream workplaces.

Recommendation 6: Establish a national mandatory reporting mechanism for restrictive practices, modelled from the Restrictive Intervention Data System (RIDS) in Victoria. This must be done with a view to facilitate the elimination of restrictive practices in disability supports via robust collection of data and information, critical analysis and guidance.

Recommendation 7: A nationally consistent screening process for working with people with disabilities should be established for any NDIS registered services, and other services receiving direct funding to deliver disability or related supports.

Recommendation 8: To maximise control and choice, no restrictions should be placed on who *self-managing NDIS participants* can employ to provide supports. The NDIA must distribute information and facilitate access to police checks, working with vulnerable people checks, and NDIA registration of the provider *if the person with disability wishes*, at no cost to the participant.

Recommendation 9: Commonwealth to establish a plan targeted at increasing accessible, affordable housing for people with disabilities in the community, including public housing and crisis accommodation.

Recommendation 10: Commonwealth to fund a national audit of accessibility of crisis shelters/accommodation, including analysis of age, gender, racial, cultural and linguistic status, for people with disabilities, followed by proactive response to address the findings.

Recommendation 11: A National Disability Justice Plan should be established, with genuine funding and legislative initiatives attached, aimed at improving the accessibility of the criminal justice system for victims as well as offenders with disabilities. This must take into account intersecting factors such as age, gender, racial, cultural and linguistic status.

Recommendation 12: Commit extra ongoing funds to expand the capacity of the National Disability Advocacy Program at least equivalent to the funds provided to service providers and carer groups, ensuring that the full range of independent, community based disability advocacy is properly funded and made widely available.

Recommendation 13: Remove the onerous compliance burdens on the NDAP advocacy sector and redirect that money back into frontline advocacy.

Recommendation 14: A national independent statutory body for complaints, oversight and monitoring should be established and co-designed by people with disabilities. It should apply to all disability services, including all supports funded by NDIS, plus all other disability services regardless of funding source. It must also be available to people with disabilities in informal unpaid care arrangements as they choose. It must be independent from the NDIA and other services.

Recommendation 15: The statutory body should complement and work in collaboration with the existing legal structures, such as the police, in recognition of the extreme powerlessness faced by people with disabilities due to societal inequalities, and their subsequent increased risk of victimisation and exploitation. It must NOT operate as a disability specific alternative to the existing justice systems.

Recommendation 16: The statutory body must be fundamentally focused on protecting the rights, will and preferences of people with disabilities. It must be imposed on providers of support, NOT on people with disabilities.

Recommendation 17: The statutory body should have broad and authentic powers to investigate and enforce findings in regards to information and complaints received by people with disabilities, community members, and other statutory systems.

Recommendation 18: The statutory body should be funded in order to meet the demand and access needs of people with disabilities. It should be allocated a fixed percentage of all other disability related spending

Recommendation 19: The statutory body should include a national community visitor scheme as part of its function.

Recommendation 20: The statutory body must address the intersecting nature of disadvantage among people with disabilities, including factors such as age, gender, racial, cultural and linguistic status. This includes collection of data disaggregated by age, gender, racial, cultural and linguistic status, and living arrangement to understand the issues and monitor improvements in accordance with the UN CRPD.

Introduction

Advocacy for Inclusion is a not-for-profit non-government community organisation in the Australian Capital Territory. This submission centres on our direct practice experience with people with disabilities, including individual advocacy support, self-advocacy support, and consultations undertaken during previous projects, as well as draws from peer reviewed research literature. We highlight consumer insights into institutional settings, and their direct experiences of violence, including two in-depth personal stories of people with disabilities, shared with their permission. These are perspectives rarely heard by the broader community.

The term 'violence' is used as a broad term in this submission to encompass abuse, neglect, and restrictive practices, because they all stem from misuse of power against people with disabilities, whether deliberate acts or otherwise. Violence against people with disabilities can manifest in unique ways compared to violence against non-disabled people, and for this reason it often goes unrecognised. This submission explores a wide range of violence against people with disabilities, from the use of generic institutional practices that deny real choice and control, to overt acts of violence that are recognised in criminal law.

Our key message is that institutional models for disability support are inherently flawed, violent by design, and must be phased out, particularly with the opportunities brought by the National Disability Insurance Scheme.

Hearing people with disabilities

The structure of this Inquiry unfortunately will have excluded many people with disabilities in institutional settings. The timeframe for submissions was very short, and the main format for submission was in writing, which excludes people who have low literacy or are physically unable to make a written submission. After contacting the Committee Secretariat, Advocacy for Inclusion was advised on 10 April 2015 that the Committee had begun a number of processes to make the Inquiry more accessible, including Easy English documents, taking submissions via telephone, and extending the closing date. We are pleased to see these measures in place. However, the repeated changes to the Inquiry highlights the level of complexity and the challenges involved in reaching the target group, which the Committee was apparently not aware of or prepared for at the outset. Consequently, the Inquiry has had very poor accessibility for much of its duration.

Even with improved accessibility, many people with disabilities in institutional settings do not have access to independent means of communication. Many do not have internet, or the capacity to privately make a phone call or write a letter without support or at least without fear of intrusion by support staff. People with disabilities also fear repercussions for speaking out, and this acts as a major barrier to hearing their views. This means that they need targeted measures to enable them to communicate with the Committee in a way that's safe, private, and supportive of their access needs. It is highly likely that the vast majority of people living in institutional settings have been unable to air their views to this Inquiry, and are altogether unaware that there has been an Inquiry. Outsiders try to reach out and contact people in institutional settings, as Advocacy for Inclusion did for this Inquiry¹; however, it is generally at the discretion of institutional staff as to whether the message gets through, as well as whether support will be offered to the person with disability to participate if they need it.

Violence in institutional settings is a hidden issue, and the fact that such an Inquiry has been unable to reach out to the people it seeks to inquire about highlights this very problem. A Royal Commission is necessary to allow the time and resources to hear the views of people with disabilities, explore the extent and complexity of the issue, and hold support providers and individual perpetrators accountable.

Recommendation 1: Hold a Royal Commission into violence, abuse and neglect against people with disabilities in institutional settings.

¹ Advocacy for Inclusion sent letters to our consumers and self-advocates informing them of the Inquiry and how to make a submission. We also invited them to contact us if they preferred to share their views through our submission.

The status of people with disabilities

People with disabilities are a marginalised group in society. They experience:

- Social exclusion and heightened risk of isolation²;
- Twenty-nine per cent less participation in the labour force compared to people without disabilities³. Australia is one of the worst performers for employment of people with disabilities in the developed world⁴;
- Two and a half times the rate of poverty in the general population⁵. The rate of poverty in Australia for people with disabilities is more than double the OECD average⁶;
- Lower levels of education;⁷
- Stigma and stereotyping;
- A serious lack of access to disability supports, with the pre-NDIS system providing only half the disability supports needed to less than half of all people with significant disabilities.⁸

In this context where people with disabilities are undervalued, socially isolated, and face extreme socioeconomic and political inequalities, they are at heightened risk of victimisation. Unequal power dynamics is a significant determinant of violence against people with disabilities.^{9 10}

There are no national studies on the prevalence of violence against people with disabilities in institutional settings, or in the general community. However, it is widely documented that people with disabilities experience higher rates of violence than the general population, and women with disabilities are at particular risk.¹¹ The Australian Bureau of Statistics data shows that 46 percent of ACT women who reported violence in the last 12 months were women with disabilities,¹² which is alarming given only 17 per cent of women in the ACT have disabilities.¹³

People with disabilities experience distinct forms of disability based violence in all settings, such as withholding essential disability aids or supports, inciting fears or paranoia of a person with mental illness¹⁴, leaving a person reliant on support in uncomfortable or humiliating situations¹⁵, and use of chemical restraint. This is compounded by other intersecting factors such as gender, age, race, and cultural status. For example, an Indigenous woman with disability might be subjected to gender, disability and race based violence in one incident or by one perpetrator.¹⁶

² Scope & Deakin University. (2013). *Australians fail social inclusion test for people with a disability*.

<http://ahha.asn.au/news/australians-fail-social-inclusion-test-people-disability>

³ Australian Bureau of Statistics. (2011). Labour force. 4446.0 – Disability, Australia, 2009.

⁴ OECD. (2010). *Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries*.

Appendix K The disability support pension. Productivity Commission Inquiry Report. No. 54, 31 July 2011

⁵ Walsh, J. (2012). Australia's health 2012: Social inequalities, health inequalities. Retrieved from www.aihw.gov.au

⁶ OECD. (2009). *Sickness, disability and work: Keeping on track in the economic downturn – Background paper*.

⁷ Australian Bureau of Statistics. (2011). Education. 4446.0 – Disability, Australia, 2009.

⁸ Australian Institute of Health and Welfare. (2009). *Disability in Australia: multiple disabilities and need for assistance*. Disability series. Cat. no. DIS 55. Canberra: AIHW.

⁹ Fitzsimmons, N. M. (2009). *Combating violence and abuse of people with disabilities: A call to action*. Paul H. Brookes Publishing Co.

¹⁰ Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

¹¹ National Cross-Disability Alliance. (2014). *Senate Standing Committee on Finance and Public Administration: Inquiry into domestic violence in Australia: Joint submission from National Cross-Disability Disabled People's Organisations*.

¹² Australian Bureau of Statistics. (2012). Personal Safety Australia 2012, 4906DO016_2012. Table 11

¹³ Australian Bureau of Statistics. (2013). Survey of Disability, Ageing and Carers 2012, Cat.No. 4430.0, Table 5.1

¹⁴ Hassouneh-Phillips, D., & Curry, M. (2002). Abuse of women with disabilities: State of the science. *Rehabilitating counselling Bulletin*, 45(2), 96-104

¹⁵ Nixon, J. (2009). Domestic violence and women with disabilities: Locating the issue on the periphery of social movements. *Disability and Society*, 24(1), 77-89.

¹⁶ National Cross-Disability Alliance. (2014). *Senate Standing Committee on Finance and Public Administration: Inquiry into domestic violence in Australia: Joint submission from National Cross-Disability Disabled People's Organisations*.

The UN Committee on the Rights of Persons with Disabilities recommends that Australia develops nationally consistent data collection and public reporting of disaggregated data across the full range of UN CRPD obligations, including the right to be safe from violence, and that all data be disaggregated by age, gender, disability status, place of residence and cultural background.¹⁷ This is critical to gain a real understanding of the issue to support the development of policies and legislation that enable people with disabilities to access basic human rights, and to prevent violence against people with disabilities.

Recommendation 2: As per international obligations and recommendations by UN treaty monitoring bodies, the Commonwealth should fund an ongoing comprehensive assessment of the situation of children and adults with disabilities to establish a baseline of disaggregated data against which compliance with UN treaties data collection on people with disabilities can be measured across the full range of UN treaty obligations.¹⁸

¹⁷ UN Committee on the Rights of Persons with Disabilities. (2013). Concluding observations on the initial report of Australia. http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUS%2fCO%2f1&Lang=en

¹⁸ National Cross-Disability Alliance. (2014). Senate Standing Committee on Finance and Public Administration: Inquiry into domestic violence in Australia: Joint submission from National Cross-Disability Disabled People's Organisations.

Deinstitutionalisation: unfinished business

The Shut In campaign defines an institutional setting as any place a person with disability has to live, work or participate in order to get the disability supports they need¹⁹. Historically, people with disabilities have faced systematic forced institutionalisation in large congregated, geographically isolated facilities, as part of the eugenics movement in the 20th century. This formed the main welfare response to people with disabilities at the time. Australia underwent deinstitutionalisation from the 1960s onward, and most of the traditional large facilities have been closed. However, this process is far from complete, with the majority of people moved into other institutional settings such as boarding houses, nursing homes and group homes²⁰. Some large institutions remain in operation, such as the Stockton Centre in NSW, which accommodates around 400 people with disabilities.

Institutional practices have been carried over to contemporary disability support systems and contexts²¹. This includes in group homes run by disability service providers, which are considered the modern alternative to larger facilities, and are not widely considered “institutions”. For example, as the Stockton Centre’s closure is underway, the NSW government reportedly plans for many residents to move into smaller supported accommodation group homes.²² New respite houses are being built in the ACT, despite the opportunities brought by the NDIS to develop innovative, inclusive models of respite support for people with disabilities in the general community.²³

Advocacy for Inclusion works directly with people with disabilities who live, work and participate in a range of institutional settings. This includes:

- Small supported accommodation settings – community based homes accommodating usually around 1 - 6 people with disabilities, which are run by services providing disability supports. These are often referred to as group homes.
- Sheltered workshops, where people with disabilities are congregated together in a segregated workplace, where disability supports are offered. These are often referred to as Australian Disability Enterprises (ADEs);
- Special schools or units – a segregated school environment or program for children with disabilities, both separate from and inside mainstream schools;
- Respite houses, where people with disabilities stay together for a short period to give their unpaid carers a break from caring responsibilities;
- Day centres, where people with disabilities are congregated together in a supported service setting to participate in recreational activities.

¹⁹ <http://www.shutin.org.au/index.php/what-is-the-issue>

²⁰ Drake, G. (2014). The transinstitutionalisation of people living in licensed boarding houses in Sydney. *Australian Social Work*, 67(2), 240-255.

²¹ Marsland, D., Oakes, P., White, C. (2007). Abuse in care? The identification of early indicators of the abuse of people with learning difficulties in residential settings. *The Journal of Adult Protection*, 9(4), 6-20.

²² Parents of residents continue their fight to keep Stockton Centre open. (5 December 2013). ABC News. Retrieved from:

<http://www.abc.net.au/news/2013-12-05/parents-of-residents-continue-their-fight-to-keep-stockton-cent/5135798>

²³ For more information: <http://www.canberratimes.com.au/act-news/ricky-stuart-foundation-plans-to-build-second-respite-centre-for-teenagers-with-a-disability-20150603-ghfeqf.html>

Power dynamic in institutional settings: a recipe for violence

Research literature indicates people with disabilities are at even greater risk of violence in institutional settings, due to the magnified power imbalances and dehumanised nature of the supports provided^{24 25}. The extreme power dynamics in these settings are a recipe for extreme forms of violence.²⁶ This has been consistently observed by Advocacy for Inclusion in our direct interactions with individual advocacy consumers and self-advocates. Institutional settings serve different purposes and vary in size and structure. However, there are several common features:

- Disability specific;
- Service driven and dehumanised;
- Distinctly hierarchical;
- Lack of respect for privacy and boundaries;
- Isolation;
- Use of restrictive practices.

These features make institutional settings violent by design, by creating problematic power dynamics and dehumanised environments that make people with disabilities vulnerable to violence, abuse and neglect. When people with disabilities have no control over their supports and environments they are powerless and become vulnerable to violence. For this reason, deinstitutionalisation is essential in preventing violence against people with disabilities.

People with disabilities need to have genuine control and choice over their supports and living arrangements so that they are no longer required to live, work or otherwise participate in specific settings or arrangements in order to get the support they need. Advocacy for Inclusion recommends that these models of support for people with disabilities should be phased out, because it is clear after many decades that it is inherently flawed²⁷ and not compliant with international human rights obligations.²⁸

Interviewer: "Overall how much choice and control do you feel you have over your life?"

Ben: "At the moment with [service provider] over my life it's practically none with them... you just feel like you're boxed in you can't do anything. And sometimes you're boxed in and you just feel awful, you know. No one should feel like they're suffering no one should feel like that."

*(Control and choice study individual interview participant, 2013)*²⁹

True deinstitutionalisation of people with disabilities requires not only a system like the NDIS that allows people with disabilities to take control of their support and living arrangements, it also requires broader structural change to enable full inclusion and participation of people with disabilities in all areas of society. Without opportunities equal to that of the general population, people with disabilities will continue to find themselves forced into living, support, and work arrangements, with no choice and control. They will continue to face powerlessness and therefore heightened risk of violence, abuse and neglect. People with disabilities need access to real jobs for real pay, political life including as leaders and representatives, public spaces, and community resources and services on an equal basis to people without disabilities.

²⁴ Chenoweth, L. (1995). The mask of benevolence: Cultures of violence and people with disabilities. *Journal of Australian Studies*, 19(43), 36-44.

²⁵ Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

²⁶ Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* USA, Maryland: Paul H. Brookes Publishing Co.

²⁷ Sobsey, D. (1994). As above.

²⁸ United Nations Convention on the Rights of Persons with Disabilities, Article 19.

²⁹ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions*.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

Recommendation 3: Institutional models of support for people with disabilities are inherently flawed and must be defunded and phased out. The Commonwealth should establish a national plan for the full deinstitutionalisation of people with disabilities.

Recommendation 4: Commit to a properly resourced *National Disability Strategy* and through that support the genuine inclusion and deinstitutionalisation of people with disabilities, and implementation of the *Convention on the Rights of Persons with Disabilities*.

Disability specific

Usually institutional settings are disability specific; they are created specifically *for* people with disabilities, not *by* people with disabilities, to provide disability specific support in a range of service contexts. People find themselves in these places not through free choice, but through a chronic lack of real alternatives comparable to that available to the general public.

In the block funded pre-NDIS system, supports are designed in a way that bundles necessities like housing or employment together with disability support. This means that the person with disability cannot take their support with them to another work place or home if they wish, and so they have no real choice over their living arrangement, employment, and recreation.

Cassandra: "my mum and dad saw [accommodation provider] and thought it would be a good place to live."

Interviewer: "did you want to live there?"

Cassandra: "I thought it was alright but I didn't feel I had any other options at the time."

*(Control and choice study, individual interview participant, 2013)*³⁰

This traps people with disabilities in potentially violent arrangements. When people with disabilities become victimised, it can take many months or years before the person is able to escape that situation, particularly in residential settings. The forced nature of these arrangements, through lack of alternatives, is a form of violence in and of itself.

³⁰ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions*.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

Service driven and dehumanised

Institutional settings for people with disabilities are *service* driven, not *service user* driven. They are designed to deliver cost-effective services to numerous people, whether congregated or across several locations. With this comes a level of regimentation. While providers generally have policies that intend or purport to deliver services that support people with disabilities to have choice and control, in practice meaningful control and choice is very limited or non-existent. Workers within these settings might feel they are offering service users “choice”, however, it is usually from a small amount of options, predetermined by the service provider.

Case study

Rose lives in a group home run by a supported accommodation provider. Rose’s support worker, Sandra, asks her what she wants to do today; does she want to go to the park for a picnic lunch or does she want to have lunch at a café? The key worker wrote up a weekly plan, based on Rose’s general interests, and it’s scheduled for Rose to go out for lunch today. Rose would prefer to go to the pool for a swim. Sandra explains “Swimming is scheduled for Fridays, when we have an extra support worker to help you in the pool. Today you get to go out for lunch. That’ll be nice, won’t it? Where do you feel like going? Or do you feel like staying home for lunch today?”

In these settings, control extends to the finest details of the person’s day to day movements and choices – they do not have what members of the general population would consider basic freedoms. For example, what a person eats, when they will eat it, and even how they will eat it.

Julia:

“I’m in bed by half past 8.”

Interviewer: “And what time would you like to stay up until?”

Julia: “Ten.”

Interviewer: “What is the reason you don’t stay up until 10 o’clock now?”

Julia: “I need two people to get me into bed and on and off the toilet. Every night at half past 7 [support provider] comes and put me on the toilet and shower and they have to leave by half past 8.”

Heather:

“They are controlling our movements, controlling what time we get home”

(Control and choice stud, individual interview participants, 2013)³¹

The ultimate power rests with the provider, who has control over the support funds, the support provision, and the service environment. Providers control what support workers enter the house and who lives in the house, and service users are often forced to cohabit. As noted above, people with disabilities do not usually actively choose to live or participate in these settings in the first place.

Steve:

“The people in my house changed. I was happy before but nobody asked me what I wanted. It made me very angry. It made me very very angry. I complained and [service provider] told me to mind my own business.”

³¹ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions.*

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

Ingrid:

Interviewer: "Do you have the option of choosing who comes to your house and when?"

Ingrid: "I don't think so. Because at our house we have 24 hour support"

Interviewer: "is that something you'd like to have more options and choice in when it comes to who comes to your house and what time?"

Ingrid: "no because it is all organised."

Interviewer: "But if you had the option of actually being involved in organising it... Would you like to be able to make those decisions?"

Ingrid: "Yeah if we could but I don't think I would be allowed to."

(Control and choice study individual interview participant, 2013)³²

A lack of control over support workers is a big stress for many of our consumers, which is discussed on page 27 under systemic workforce issues.

This power dynamic allows violence against people with disabilities in institutional settings to thrive, with very limited access to redress for victims. People with disabilities do not feel entitled to complain or to report violence, and/or they fear the repercussions of speaking up given their dependence on the provider to meet their most basic needs. When a person with disability has a complaint about their services, they rely heavily on the provider to listen and make changes. They do not have the power to negotiate with the service provider, who can easily dismiss their complaints.

Steve:

"I'm not allowed. Oh boy. I can't favour some people [support workers] over other people... It is very hard. You have to put up with people you don't like.

I complained and [service provider] told me to mind my own business. My father helped me. He complained but nobody listens.

I don't like complaining because every time you complain you feel like you're a problem."

Ben:

"They say that everyone has the right to make a complaint and for them to hear about it but in cases like this you know it is difficult ... Sometimes I just can't complain to the agency. Like I complained once to the agency and it just fell on deaf ears."

Julia

Interviewer: "Have you spoken to anyone about the fact that you want to stay up later?"

Julia: "I don't think it's going to happen."

Interviewer: "How come you think it wouldn't happen?"

Julia: "I think it's up to the office."

(Control and choice study, individual interview participants, 2013)³³

Distinctly hierarchical

Consumers at Advocacy for Inclusion tell us that support workers are "above" them, and have more rights than them. The institutional settings effectively become the workplace of support workers first, and the homes (or workplace in the case of sheltered workshops) of people with disabilities second. Fair dismissal, with the

³² Advocacy for Inclusion. (2013). As above.

³³ Advocacy for Inclusion. (2013). Ask me. I make my own decisions.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

appropriate 'proof' of wrongdoing, seems to be a concern for organisations, at the cost of the safety of people with disabilities.

Elizabeth: "There was one guy and he took drugs at work. Methamphetamines or something I thought. Anyway one day he came in and I did not want him to hoist me. It took us two years to get rid of him. There were two of us me and someone else complained. Two years to get rid of him because he worked for the government and they would not get rid of a government worker unless we like proved it when we did many complaints and all.

In the end another guy he was shaving [co-resident] and he was rough to him... He worked in the morning and he was so rough I wouldn't let anyone treat me like that. I can't remember the details by I did complain more than once but not much response."

*(Control and choice, study individual interview participant, 2013)*³⁴

Within these settings support workers implement practices that can create a social distance between them and people with disabilities, which has the effect of othering and devaluing people with disabilities.³⁵ For example, Advocacy for Inclusion staff have witnessed how employees hired to provide disability support in sheltered workshops sit separately from disabled employees during lunch, with the exception of one or two support workers present to provide supervision.

We have worked on sheltered workshop cases where the person with disability was required to ask permission to go to the bathroom, and was not allowed access to mobile phones at all. Rules about use of mobile phones and frequency of toilet breaks are common in workplaces, but the particular power dynamic in sheltered workshops is magnified, degrading and dehumanising, particularly in a context where disabled people are paid as little as \$1 per hour³⁶. Importantly, these same rules were not applied to the employees providing support to people with disabilities, highlighting the social hierarchies that form in these settings, where people with disabilities are afforded little authority over even the basics of day to day activities. When people with disabilities are given a devalued status in this way, they are at heightened risk of victimisation, and of not being taken seriously when they raise concerns.

Although it is often believed that people with disabilities can only work in segregated settings, models established overseas shows that people with high support needs can work in real jobs for real pay in mainstream workplaces provided they have access and support to do so.³⁷

Recommendation 5: Commonwealth to fund support for people with disabilities to have real jobs for real pay. Sheltered workshops must be phased out with funds diverted toward creating access and support in mainstream workplaces.

Direct support workers can also feel powerless in their capacity to influence organisational structures, and resist established practices and cultures. This creates a problematic incongruity between their actual and perceived capacity to exercise power over people with disabilities³⁸, meaning that they might lack critical awareness of their use of power over service users, and instead feel victimised themselves.

³⁴ Advocacy for Inclusion. (2013). *As above*.

³⁵ Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). 'It's pretty hard with our ones, they can't talk, the more able bodied can participate': Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research* 54(4), 363-376. Doi: 10.1111/j.1365-2788.2009.01154.x

³⁶ See information about the BSWAT scheme here: <http://www.pwd.org.au/admin/top-5-problems-with-the-bswat-payment-scheme.html>

³⁷ See for example work by Christy Lynch in Ireland. <http://content.iospress.com/download/journal-of-vocational-rehabilitation/jvr00162?id=journal-of-vocational-rehabilitation%2Fjvr00162>

³⁸ Strand, M. L., Benzein, E., & Saveman, B. (2004). Violence in the care of adult persons with intellectual disabilities. *Journal of Clinical Nursing*, 13, 506-514.

In Advocacy for Inclusion's experience, support workers fear repercussions and sometimes contact us anonymously to alert us to issues in supported accommodation settings. Unlike people with disabilities, support workers have their own lives and homes to return to at the end of a shift, and for this reason they are better positioned to speak out about violence against service users. The fact that support workers hold such fear for repercussions highlights that this is a pervasive organisational and cultural problem, and that people with disabilities face extreme powerlessness in these environments.

Lateral violence

In spaces where people with disabilities have little to no control and choice, and where power is exercised over them to extreme degrees including through physical force, people with disabilities can become violent toward each other or toward support workers as a form of protest. This issue is often referred to as "challenging behaviours", and dealt with via restrictive practices, such as the use of psychotropic medications. This is important to highlight because it is often wrongly perceived that people with disabilities are safer in institutional settings where they are "cared for" and "with their own kind". In our experience, lateral violence is very common in institutional settings but is very poorly recognised as a serious issue with major impacts on people with disabilities.

Haley³⁹

Haley is 40 years old and was placed in a three bedroom home with another woman with disability, Vanessa. Their home was run by a supported accommodation provider, and staffed 24 hours a day. Haley had recently moved out of her family home. Haley wanted to move out, but she did not particularly want to live with Vanessa, who she'd met only once before as part of a meeting arranged by the service provider. Vanessa had been living there on her own for a few months. She would often go into Haley's room and touch her things, and was very noisy throughout the night. Haley had problems sleeping, had no privacy. She told her support workers and the service provider team leader that she hated living with Vanessa. The team leader replied "that's not a very nice thing to say. Give it time, you'll get used to each other".

Soon Haley and Vanessa began yelling verbal abuse at each other, and this escalated to physical violence, when Vanessa started biting, scratching and pulling Haley's hair. After that, the service provider installed locks onto Haley's room so that she could lock herself in when she wanted to keep Vanessa out. Haley felt afraid to leave her bedroom and she dreaded coming home from the day centre.

Haley was highly stressed. She would scream, damage property and hit staff. The support workers gave Haley prescribed medications to help calm her down, on average every week, when it had only been used once or twice a year while she was living at her parent's house. The house was in a constant state of damage, and there was a very high turnover of support staff. Haley also witnessed a support worker slap Vanessa on the face after she had thrown her lunch on the ground. Haley was afraid, she was so tired, and she couldn't handle it anymore.

A support worker concerned about the situation contacted Advocacy for Inclusion secretly and put Haley onto the phone to explain what was happening. With Haley's permission, the advocate then worked alongside Haley, who wanted help to find somewhere else to live. Haley preferred not to go to the police about the issue because she thought it might get her into more trouble. The advocate sent many complaints, contacted senior managers at the government department funding the provider, and attended many meetings, advocating alongside Haley for her right to live in a safe environment. The government department explained that there simply aren't any vacancies available anywhere at this point in time, which could meet Haley's support needs.

³⁹ Haley's case study is based on several cases at Advocacy for Inclusion, which outlines the sorts of situations people with disabilities experience in residential settings, and how it impacts them personally.

They offered to arrange for more outings for Vanessa and to partition part of the home so that Haley had more space, in an attempt to manage the situation.

The advocate also asked Haley if she wanted to access counselling for emotional support, and subsequently connected her to a psychologist. The support provider had not yet identified this need, even though Haley had been subject to violence in her home for a long period, and she expressed high levels of distress.

It wasn't until the day that Haley tried to set her house on fire, after almost a full year of violence, that the service provider took action. Haley was supported to move into a different home. She is much happier there and she rarely needs to use the medications anymore that she was given to help calm her down in her previous home.

In Advocacy for Inclusion's experience, lateral violence occurs over long periods, by the same perpetrator or by several, until what is considered by service providers to be a critical incident, such as a major physical assault, property damage, or life threatening self-harm, results in action being taken. Often Advocacy for Inclusion is not alerted to the problem until it has been going on for a long time. Service providers appear to have difficulty conceptualising lateral violence as a serious matter that must be dealt with urgently, and exhibit a different sense of responsibility and duty of care than if a staff member was engaging in the same behaviour.

Service providers also seem to lack understanding of the adverse impacts on people with disabilities, and even once action is taken, rarely do they take initiative to support the victim to access professional counselling or other victim related supports. As has also been documented in the research literature, there is an apparent desensitisation to violence in these settings. Violence has become part of the norm.^{40 41}

Haley's case study shows the lack of choice for both Haley and Vanessa in the first instance when Haley was placed in Vanessa's home. The service provider failed to acknowledge and respond to the early signs of violence when Haley told support staff and the team leader that she did not like living with Vanessa, and when Vanessa breached Haley's personal space and privacy. The service provider attempted to manage overt physical violence within the service setting using restrictive practices, including environmental restraint (allowing Haley to be in a situation where she was required to lock herself in her room because she was unsafe to leave) and chemical restraint (using medications in response to Haley's distressed behaviour).

Outsiders were only involved when a worker contacted Advocacy for Inclusion secretly, because they feared retribution for taking the matter outside the organisation, indicating a culture of covering up and blocking outside scrutiny within the organisation. Even with the advocate's support, it was extremely difficult to have the organisation acknowledge the significance of the problems and respond appropriately. Independent community based advocacy is vital for people with disabilities to access outside support, however it is limited in that it has no statutory authority to require service providers to act.

A reminder that this case study is formed from several cases that Advocacy for Inclusion has worked on. It is not an isolated or occasional incident or situation, rather these circumstances are very common and represent the tip of the iceberg.

Lack of privacy and boundaries

With extreme powerlessness and dehumanisation comes erosion of respect for privacy and boundaries of service users. In institutional settings, people with disabilities have little opportunity to undertake private

⁴⁰ Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

⁴¹ Strand, M. L., Benzein, E., & Saveman, B. (2004). Violence in the care of adult persons with intellectual disabilities. *Journal of Clinical Nursing*, 13, 506-514.

activities without the presence or intrusion from support staff, or without the expectation that they seek permission first. People with disabilities are not afforded the right to make decisions about their own consensual intimate relationships, or to undertake what the general community would consider deeply private activities in private, such as masturbating and personal care.

Claus:

"I wasn't home at one stage and the next minute they [support worker] were already inside the house and I've got no idea how they got in. I rang up [the service provider] and said they have to wait in their car until I get home and that's that. How would you like it if someone came into your place if you weren't home?"

Interviewer: "I wouldn't like it at all."

Claus: "You see it's the same thing."

Ben:

"I want to find someone [service provider] who is not so strict on their rules... If I get a girlfriend I feel too embarrassed to bring her back to the house. It's against their religion for one thing. I have to take her somewhere else... It's the way that they operate there's nothing I can do about it."

(Control and choice study, individual interview participants, 2013)⁴²

For many people with disabilities, they have been subject to this lack of respect from a young age⁴³, including in school environments (both special schools and mainstream) where children with disabilities are treated differently to other children.⁴⁴ This sets the expectation for people with disabilities that they do not have the right to bodily autonomy in these environments, and encourages ambiguity around what is and what is not acceptable or abusive behaviour. It makes it difficult for people with disabilities to recognise when someone is violent towards them, or to feel they have the right to complain or report it. It also encourages an environment wherein support workers feel entitled to disregard boundaries. The line between quality support and violent or negligent behaviour becomes blurred. For example, where a person requires support to shower and groom themselves and the support worker performs these tasks in a manner that is painful, uncomfortable or humiliating for the person.

Elizabeth: There was one guy and he took drugs at work. Methamphetamines or something I thought. Anyway one day he came in and I did not want him to hoist me. It took us two years to get rid of him.

(Control and choice study, individual interview participant, 2013)⁴⁵

Isolation

Contemporary institutions, such as small group homes, are usually geographically located within the general community. However, people with disabilities still become isolated in these settings from genuine connections with the general community and from natural, freely given relationships, such as family and friends.

Elizabeth: "There is a few times lately that I've wanted to go out ... They said 'well actually it's a residential complex here we're not supposed to be doing that.' I would like to at least go to [name of

⁴² Advocacy for Inclusion. (2013). *Ask me. I make my own decisions.*

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

⁴³ Fitzsimmons, N. M. (2009). *Combating violence and abuse of people with disabilities: A call to action.* Paul H. Brookes Publishing Co.

⁴⁴ See for example this article about a 14 year old girl with disability who had her arm pits forcibly shaved as part of a life skills program for children with disabilities at school: Young, S. (2 June 2014). 'Life skills' program teaches wrong lesson. *ABC Ramp Up.*

<http://www.abc.net.au/rampup/articles/2014/06/02/4017221.htm>

⁴⁵ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions.*

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

suburb] shops for a coffee ... Aren't there rules in disability where they've got to take people out into the community?"

*(Control and choice study, individual interview participants, 2013)*⁴⁶

Most consumers at Advocacy for Inclusion participate in numerous institutional settings. For example, they live in supported accommodation, work in a sheltered workshop, and attend a day centre, resulting in very minimal meaningful interactions with the world outside disability service settings. For people who live in supported accommodation or other institutional settings, even when they participate in mainstream contexts they are often accompanied by institutional support workers, who interact with the outside world on their behalf, or at least act as a supervisor.⁴⁷ This means that for some people with disabilities institutional structures follow them everywhere they go, especially those who have high support needs and are isolated from all natural networks. Effectively many spend the majority if not all of their time within an institutional bubble, even when physically outside the walls of such settings.

This also means that people with disabilities are gate kept by service providers. Consumers of Advocacy for Inclusion who live in supported accommodation rarely receive their mail directly, if at all, and are unable to access the phone and email in privacy or independently. Providers are able to use their discretion as to whether they will allow outsiders to make contact with service users. People with Disability Australia's (PWDA) recent facilitation of the NDIS Citizen's Jury highlighted a clear example.⁴⁸ PWDA tried to contact people with disabilities living at the Stockton Centre 5 times to hear their feedback on the NDIS, but they were blocked each time. This is part and parcel of institutional living and it is exceptionally rare for such issues to be made so publicly visible.

Isolation and gate keeping creates a lack of outside oversight and compounds power imbalances. It makes it difficult if not impossible for people with disabilities to seek help from the outside, particularly when they might not know anyone outside the provision of disability support services. It also minimises the opportunities for outsiders to identify problematic practices or violence. The environments become very insular, allowing violent cultures to thrive without scrutiny.

Restrictive practices

In addition to the overall restrictive nature of institutional settings, which we believe should be conceptualised as violent, restrictive practices are actively used against people with disabilities and sanctioned as "support practices".

Restrictive practices "are the deliberate or unconscious use of coercive power to restrain or limit an individual's freedom of action or movement. There are five main forms of restrictive interventions: chemical, environmental, mechanical, and physical restraint, and seclusion."⁴⁹

In our advocacy experience, in disability service settings restrictive practices are viewed as legitimate behavioural management or support techniques in response to behaviours which may have escalated to aggression or agitation – commonly known as "challenging behaviours" – but which have arisen out of unmet needs. These needs have not been catered for by the disability support system, or have not been properly

⁴⁶ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions*.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

⁴⁷ Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

⁴⁸ Morton, R. (16 May 2015). Staff at NSW institution 'kept disability jurors from clients'. *The Australian*.

<http://www.theaustralian.com.au/national-affairs/health/staff-at-nsw-institution-kept-disability-jurors-from-clients/story-fn59nokw-1227356889311#disability>

⁴⁹ Spivakovsky, C. (2012). *Restrictive Interventions in Victoria's Disability Sector Issues for Discussion and Reform*.

<http://www.publicadvocate.vic.gov.au/file/Restrictive%20interventions%20discussion%20paper.pdf>

understood or responded to by support people. Paul Ramcharan's discussion in understanding challenging behaviours is helpful. He writes that these behaviours:

“can be understood better as adaptive behaviours to maladaptive environments. These behaviours can be seen as forms of ‘resistance’ or ‘protest’.

“Behaviours of ‘resistance’ and ‘protest’ should be seen as legitimate responses to difficult environments and situations, and not a reason for restrictions designed to change the person and their behaviour.

“Changing the person and their behaviour should not be the starting point. Rather, it is necessary initially to examine how to change services, systems and environments as a means of changing behaviour.”⁵⁰

Significantly, restrictive practices are used when people with disabilities “act out” in response to violence targeted at them, and as discussed earlier, in response to pain, discomfort, unmet need and extreme powerlessness in institutional settings. Many people with disabilities in institutional settings have some form of communication impairment. It can make it difficult for them to articulate that they are being abused, or they are simply not listened to or believed because of discriminatory attitudes based on their disability. Advocacy for Inclusion has worked on several cases where chemical restraint – the use of psychiatric medications – was used to help the person “calm down” during periods of escalated behaviour, when it subsequently came to light that the person had been subject to violence during that period. An example of this is illustrated in Zafir's story below on page 22.

Restrictive practices can also be used to degrade, humiliate, discipline, control, or coerce a person with disability.⁵¹ They are used out of convenience or for cost effectiveness because restrictive practices may be cheaper in the short term than implementing additional supports. For example, Advocacy for Inclusion worked on a case where a person's taps were removed to prevent the person with disability from freely using the taps because the plumbing was noisy and causing problems for the neighbour.

Restrictive practices are fundamentally violations of human rights. They can cause physical and psychological discomfort or pain, deprivation of liberty, alter thought processes and deprive a person of their property.⁵² These practices can have significant adverse impacts on the person's mental and physical health and wellbeing.⁵³

Advocacy for Inclusion's experience tells us that it is a practice widely hidden from the broader community. A key feature missing from the current system is accountability measures. Because restrictive practices have serious consequences and are a form of violence, these practices must be strictly accounted for and monitored, yet they are not. Support systems and services must be drastically improved so that people with disabilities are better supported to communicate and have their needs met in order to prevent the use of restrictive practices in the first place.

⁵⁰ Ramcharan, P. (2009). *A view from people with disabilities and family carers: A final research report to the Office of the Senior Practitioner*. Page 2. Retrieved from

http://www.dhs.vic.gov.au/__data/assets/pdf_file/0008/608588/osp_experiencesofrestrictivepractices_pdf_0509.pdf

⁵¹ CRPD Civil Society. (2012). *Disability rights now: Civil Society report to the United Nations Committee on the Rights of Persons with Disabilities*.

⁵² CRPD Civil Society. (2012). *Disability rights now: Civil society report to the United Nations Committee on the Rights of Persons with Disabilities*.

⁵³ Spivakovsky, C. (2012). *Restrictive Interventions in Victoria's Disability Sector Issues for Discussion and Reform*. <http://www.publicadvocate.vic.gov.au/file/Restrictive%20interventions%20discussion%20paper>.

We recommend a national mandatory reporting approach, modelled on the Restrictive Intervention Data System (RIDS) in Victoria (as outlined in the consultation paper), with an aim to eventually eliminating restrictive practices.

The current *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* has a number of major weaknesses, including that it is not enforceable and therefore does nothing to improve accountability or transparency. It fails to use the social model of disability to conceptualise “challenging behaviours” and restrictive practices.

It also lacks critical analysis of the subjective nature of “last resort” as a concept, and the challenges in applying this concept in practice, particularly when staff are inexperienced and lack supervision. In short, this framework is grossly inadequate, lacks robust exploration of the issues surrounding restrictive practices and how they might be eliminated, and clear guidance for support providers.

With appropriate supports restrictive practices can be eliminated. The NDIS provides access to these appropriate supports, with increased funding and consumer control. However, there needs to be a nationally consistent approach to monitoring and regulating these practices particularly while old practices continue under the NDIS until cultural change is achieved.

Recommendation 6: Establish a national mandatory reporting mechanism for restrictive practices, modelled from the Restrictive Intervention Data System (RIDS) in Victoria. This must be done with a view to facilitate the elimination of restrictive practices in disability supports via robust collection of data and information, critical analysis and guidance.

Direct personal stories of violence, abuse and neglect

Advocacy for Inclusion gained permission from two people to share their direct experiences of violence, the impact upon them and the responses they received.

Zafir's story⁵⁴

Zafir is a young man in his mid-twenties. He attends a day centre for a few hours three days a week and he needs support to do most things throughout the day. Zafir is given anti-psychotic medications to address challenging behaviour, including self-harm, which is prescribed by his psychiatrist. Zafir does not use much verbal communication, but he can express himself using vocal sounds and hand gestures, and occasionally some words.

An advocate at Advocacy for Inclusion had been working with Zafir on and off since 2009 on a range of issues. In 2013 the advocate became aware that staff at the day centre had been giving Zafir anti-psychotic medication more frequently, and that his challenging behaviour was becoming more of a problem in that setting. This continued for about 9 months, until in early 2014 the CEO of the day centre contacted our advocate to inform her that day centre staff had reported a serious incident of physical violence against Zafir by the senior support worker at the day centre. The senior support worker had been an employee at the day centre for 17 years. The CEO had already contacted the police, who advised her to contact Zafir's legal guardian or advocate to support him to make a police report.

Deidentified day centre staff incident report

Today Zafir was verbally and physically abused by my team leader, Paul. Zafir had finished eating his carrots and was banging the container on the table. Paul yelled "stop banging that fucking container" and grabbed Zafir and pulled him out of his chair and pushed him across the room. Then Paul yelled at him again "get in the fucking corner you Muslim fuck." Zafir immediately went to the corner and looked at Paul over his shoulder. Then Paul yelled "don't look at me". Then he went and placed his hand on the back of Zafir's head and banged it into the wall. It was hard enough that I saw the gyprock wall break free from the corner.

There have been other instances involving Zafir:

- Zafir got dropped off to [day centre] and Paul was quite polite and gave Zafir a friendly touch of the knuckles and said "how are you going mate?" Later that same day Zafir came up to Paul and held out his fist for a friendly touch again and Paul threw his hand and said "no don't fucking touch me".
- We were at Macdonald's for a morning snack and Paul threw Zafir's pancakes in front of him. As Zafir was putting the butter on them and he gave a cough in Paul's general direction. "Don't cough on me" Paul said, then he went around to Zafir and gave a large cough in his face and then again on his pancakes.
- Paul and I were going for a walk with Zafir with one of his peers when I saw up ahead that there was someone walking two large dogs. Knowing Zafir was scared of dogs I suggested we change the plan of the walk. Paul disagreed and said "nah fuck him". When we were getting closer Paul told Zafir to stay close.

⁵⁴ All details included are actual details from Zafir's case, including incident reports and excerpts. All individual and agency names (including Zafir's) have been changed to protect Zafir's privacy. This story is shared with permission from Zafir's legal guardian.

- We went for a walk it was winter and quite cold. Zafir had no jumper and jacket and I suggested we should not go, fearing Zafir might get a cold. Paul said not to worry about Zafir, “fuck him”. I took my jacket off and gave it to Zafir and Paul said I was too kind.
- We were at Macdonald’s and we were having lunch. Zafir was tapping both his legs. This was annoying Paul and he made Zafir get up and stand facing the wall.
- Many times Zafir is very verbal in the car. Paul always gets very mad at this and says things like “black boy shut up, stop your Muslim fucking wailing, ZAFIR SHUT THE FUCKING HELL UP”.
- We were at the park for lunch and Zafir was taking his time with his lunch. Paul got impatient and threw his lunch on the ground. This happened a couple of times.
- Zafir was sitting on the couch being very verbal. Paul got mad and picked the side of the couch up tipping Zafir off the couch and the couch landed on top of him.
- We were off on a program and Zafir went to sit in the front seat and Paul said “no fuck you get in the back – my country, my rules”.
- We were bowling and Zafir went to pick up a bowling ball and Paul said “no pick up that ball” pointing at it. I didn’t understand what was wrong with Zafir choosing his own ball. Paul hasn’t done the same with [other clients].

Another day centre worker’s incident report outlines that over the course of many months (the exact time frame is not clear) they observed “several instances of inappropriate behaviour toward clients” by Paul. It reads “Paul uses racial abuse and taunting, particularly towards Zafir who is from a Muslim family”. It outlines that the reporting staff member and two other staff decided to confront Paul and tell him they did not agree with the way he treated clients, especially Zafir. Over the next 6 months leading up to the assault that prompted the CEO to phone the police, incidents continued to occur, and Paul sometimes apologised and refrained from abusive behaviour for a while. The incident report also outlines the way the staff member tried to address Paul’s behaviour directly by “pointing out to him the behaviours of concern as they happened... but the result is often unsatisfactory due to Paul’s highly agitated state at the time of the incident. Therefore, I would sometimes prefer to wait until Paul had calmed down”.

Response by direct support workers

Zafir experienced an intersection of race based and disability based violence, for example by Paul withholding appropriate supports, applying force and physical violence while undertaking his support responsibilities, intimidating him because of his communication style, at the same time as using racial slurs. The violence was emotional, psychological and physical and occurred at least over the course of around 9 months. It is apparent that Zafir’s increased “challenging behaviours” were in response to the abuse targeted at him by Paul. However, support workers did not take serious action until the final assault by Paul against Zafir when Paul slammed Zafir’s head into the wall. It is clear that even staff members who did report to Paul felt intimidated by his behaviour, and did not know how to respond in an effective and appropriate manner, for example by contacting the police in response to criminal offenses, including racial vilification and physical assault.

Response by senior manager

The advocate at Advocacy for Inclusion informed Zafir’s psychiatrist of the details of the assault and the patterns of violence against him by Paul, given the significance of this to his mental health and the increased use of medications to restrain him. The psychiatrist wrote a report which included documentation of the assault and preceding violent behaviour, and made reference to Zafir’s “worsening” behaviour for some months. The day centre CEO subsequently wrote a reply letter, which reads:

I was shocked that confidential and private information had been mentioned in a required objective report, particularly the disclosing of the names of two [day centre] staff members and that such emotive language as “having his head slammed against a wall” was used which was incorrect – the participant’s head was pushed into a wall, not slammed. There was no sign of physical injury to Mr [Zafir] and no mark on the wall. Mr [Zafir] had not been physically abused prior to this incident – he definitely had been racially abused. There were misleading comments made in your report and Mr [Zafir’s] behaviour at [day centre] has not deteriorated since the incident nor indeed before.

I find your comments in the report unnecessarily inflammatory and possibly in breach of privacy and confidentiality.

The CEO took appropriate action by contacting the police and dismissing Paul immediately. However, the defensiveness in response to outside scrutiny is very clear, and reflects how organisations typically respond to allegations of violence, in Advocacy for Inclusion’s experience. The CEO expresses a clear concern with saving face, particularly in the way they speculated that Zafir’s head was “pushed” not “slammed”, as though this makes a significant difference to the seriousness of the assault and misuse of power. The CEO’s denial of previous physical assaults is also striking, given that the CEO is not typically present during direct support activities, and at least two staff members had documented clear, long term patterns of physical violence. The CEO seems to express a sense of entitlement to conceal some of the details of the violence, as though this information belongs to the organisation, and not to Zafir as the service user and victim.

This kind of defensive response by service providers is a major barrier to the safety of people with disabilities in institutional settings, because it discourages people with disabilities and support workers from telling outsiders, such as authorities, about what is going on. Managerial staff are often concerned with protecting the organisation as the first priority, to avoid major consequences to the provider. Very similar patterns have been identified throughout the Royal commission currently underway into child abuse.

As explored earlier, the nature of institutional settings, as hierarchical, insular, service driven and dehumanised allows for cover-ups to be more readily undertaken, with direct support workers tending to try to manage the situation from within rather than reach out. It is deeply concerning that “Paul” was working in this setting for 17 years, and potentially had been violent to many other people with disabilities over a long period.

It highlights that although service providers are there to support people with disabilities, they have conflicted interests. Because of this, support providers cannot be trusted with managing organisational and individual violence. Outside scrutiny and intervention is essential, and people with disabilities need access to ample independent advocacy including through community based disability advocacy organisations, as well as statutory authorities.

Police investigation

The advocate at Advocacy for Inclusion worked closely with Zafir and his mother, who is his legal guardian, throughout the police investigation. Zafir became visibly distressed at the police station when his mother was being interviewed, indicating he had some understanding that they were discussing Paul’s violence against him. Although Zafir could not explicitly articulate his personal wishes in terms of pursuing the case at that time, Zafir’s mother was determined to follow this through for him and for other people with disabilities who might be supported by Paul in the future. Despite the two support workers willing to come forward as witnesses, the police decided not to charge Paul and instead give him a warning. The police said that the reason they would not charge Paul was because there was not enough evidence; Zafir was not a reliable witness because of his cognitive and communication impairments, and he could not make a statement in conventional formats. They noted that Paul expressed significant remorse and also suggested that the process would be too stressful for Zafir and his family.

It is deeply concerning that Paul was not held to account through a court hearing. Paul could be working for another agency with other people with disabilities, and Zafir might come across him again in the future in

another service setting. In the ACT, support workers are required to undergo a working with vulnerable people clearance. The warning issued by police should be detected by this screening process, and Advocacy for Inclusion alerted the Office of Regulatory Services responsible for administering working with vulnerable people clearances of the danger posed by this worker. However, it is possible that he could be granted a clearance and allowed to continue work with people with disabilities.

Michelle's story⁵⁵

Michelle gave permission for her story to be shared in her words in this submission, which she also presented at a Domestic Violence Prevention Council / Women with Disabilities ACT seminar in 2014, *intersectionality and the incidence of violence against women with disabilities*:

I live in a group house and sometimes it's ok. Some of the staff are nice. But some of them are horrible. They call me names. I'm sick of living there and I want to move out.

I was sexually assaulted by a worker in my bedroom. I reported it to the police and it went to court. One of the workers told the court that it didn't happen. They didn't believe me and the man who abused me got let off.

I never got any closure. I saw him one day in public. It made me cry. Why did he get let off? He got fired but I wonder if he's working with other disabled people now. I worry for their safety.

My house brings up painful memories. It hurts a lot. It makes me quite upset. I moved into a different bedroom so that I don't have to remember it so much. I can make my own decisions about where I live, but for now I am stuck there.

Sometimes I get frustrated. But I am ok now. I am a very strong woman and I know I can do it.

Advocacy for Inclusion provided advocacy support to Michelle for several years to achieve the living arrangement she wanted. She lives in a group home run by a supported accommodation provider, which is currently block funded. She drew up a plan with her advocate outlining the living arrangement she wanted but due to a lack of access to individualised disability supports and affordable housing she is still waiting to move into a home of her choosing. She has recently been through the NDIS planning process and will soon access the disability support she needs to move out of her current arrangement. She has now waited for five and a half years since telling her advocate that she wanted to move. The lack of access to individualised funding has caused her to be trapped in her current living arrangement. She is unable to simply move into another home, even if one was made available to her.

Michelle experienced gender based as well as disability based violence. She refers to some of the staff who are "horrible" and call her names, and she also refers to the long-term impacts of trauma and facing constant reminders in her living environment where the assault happened several years earlier. Her support worker abused his power, as someone in a position of trust and responsibility, at a time when there was no other support workers nearby to stop him. Michelle was unable to access justice through the court system, as the absence of other witnesses meant that her case was viewed as not having enough evidence. In supported disability service settings, people with disabilities are often alone with support workers in order to provide a range of personal supports, such as showering, toileting and dressing.

The justice system failed both Zafir and Michelle, and a lack of responsiveness to disability and disability specific contexts seems to have played a major part. For Zafir, his non-conventional communication needs were totally overlooked in his interactions with police. It was also assumed that it would be too stressful for him

⁵⁵ Michelle gave permission for her story to be shared and her first name to be identified.

to go through the court process because of his disability, yet disability appropriate supports were not offered. Despite clear patterns of racial and disability abuse and assaults by “Paul”, the police did not appreciate the danger Paul poses to other people with disabilities, who he might go on to work with in other workplaces, and therefore the importance of charging Paul and having him go through a court hearing. For Michelle, her perpetrator was not convicted and he too might be working in other settings with people with disabilities.

Systemic workforce issues

There are a range of systemic workforce issues in the disability sector. People with disabilities have told Advocacy for Inclusion that they are particularly concerned about the following:

- The wrong sorts of workers employed
- No control over staff recruitment and dismissal
- High staff turnover

The wrong sorts of support workers employed

Brendan: I remember a long time ago there was a man who worked at [supported accommodation agency]. It was a long time ago. He said "If I wanted to I could break your neck". He put his arms around my throat. He said I could break your neck. Because he didn't like what I said. People like that don't belong in disability.

Facilitator: Did that worker end up getting dismissed?

Brendan: No. Nobody believed me.

(Focus group responses. Topic: safety in disability services)⁵⁶

People with disabilities tell us of horrific violence against them by support workers who deliberately set out to hurt and exercise power over them. Zafir's and Michelle's cases provide examples of this. While the issue of violence, abuse and neglect is a cultural and structural issue – a problem with institutional and societal norms and structures – some individuals seek out workplaces where they will be placed in a position that might allow opportunity to misuse power and harm people.⁵⁷ Thorough screening processes to prevent such people from entering the disability sector are therefore highly important.

Brendan's case echoes the issues experienced by Zafir and Michelle in not being listened to and believed. It highlights that although overt violence was perpetrated by an individual in those cases, the characteristics of institutional settings outlined earlier allow violent behaviours of individual staff members to thrive.

Recommendation 7: A nationally consistent screening process for working with people with disabilities should be established for any NDIS registered services, and other services receiving direct funding to deliver disability or related supports.

No control over staff recruitment and dismissal

Consumers tell us that at the very least they want to have the opportunity to interview their support workers before hiring them and to be able to dismiss staff they feel are not doing a satisfactory job, or simply do not feel comfortable being supported by them. Sometimes people with disabilities feel uncomfortable with particular workers, even when they feel the worker is capable of doing their job satisfactorily. For example, a personality clash. Support workers are required to undertake very personal, intimate tasks, such as toileting and showering, and it can be highly stressful and degrading to have to accept support from a worker that the person is just not comfortable with. Self-advocates at Advocacy for Inclusion link a lack of control over who supports them with neglectful staff practices.

Elizabeth: "When I had a bit more control over who was working for me I would be able to ring the agency and say no I don't think that worker is any good. That means they would have more care. You

⁵⁶ Advocacy for Inclusion facilitated a focus group to assist with National Disability Services' (NDS) Zero Tolerance Project. The Zero Tolerance report can be found at: <http://www.nds.org.au/projects/article/194>

⁵⁷ Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* USA, Maryland: Paul H. Brookes Publishing Co.

know like here I came back here from [holiday] and the place was a horrible mess. You might ring the agency and say you did not want these workers here. They would not let the place become a mess. So by not having that there seems to be like a poor work ethic or lack of responsibility. They don't care that much about the quality of their work"

*(Control and choice study, individual interview participants, 2013)*⁵⁸

The NDIS opens the way for more control and choice, however cultural change is required to ensure that the principles underpinning the NDIS are carried over into practice. Our consumers are still experiencing a severe lack of control and choice over their services even as they transition to the NDIS, because service providers are maintaining old practices in the new system.

Recommendation 8: To maximise control and choice, no restrictions should be placed on who *self-managing NDIS participants* can employ to provide supports. The NDIA must distribute information and facilitate access to police checks, working with vulnerable people checks, and NDIA registration of the provider *if the person with disability wishes*, at no cost to the participant.

High staff turnover

Our consumers tell us that the high level of staff turnover and burnout is a major concern for them, as well as a lack of preparedness among new workers to work safely with them. They feel safer with staff who have become familiar with their individual support needs, and who have established rapport and trust with them. Many feel stressed and frightened when strangers come into their home, or are generally anxious about the next time a stranger might turn up. It is obvious as to why a person might feel anxious about a stranger coming to their home, particularly to provide essential, often intimate supports. Compounding this, many of our consumers have been hurt by unfamiliar support workers in the past, on purpose as well as accidentally when the support worker has not understood how to meet their basic needs because of a lack of familiarity.

Ingrid: "Sometimes I say to the staff 'who's on in the afternoon or who's on in the morning?' and they say 'why do you want to know?' And I say 'cause I just want to know who's on so I'm not nervous if we've got strange people or if I don't know them.'"

*(Control and choice study, individual interview participants, 2013)*⁵⁹

People with disabilities often do not want to have to explain every little thing to every new support worker when they begin a shift. Although they want the support worker to listen and take instruction from them on the job, they often want the worker to be at a level of preparedness by the time they commence work by being given time to have a handover from a familiar support worker and read files about the individual needs of the person.

Support workers also need on the job supervision and instruction from staff who are already familiar with the supported person. Our self-advocates told us that while their service providers have policies instructing staff to read files and have a handover, they feel that staff are not often afforded the time to do so in practice, and are required to undertake practical duties immediately when they begin their shifts. Self-advocates also identified that when support workers are afforded the time to prepare for their shift, they have not necessarily used it for its purpose. For self-advocates participating in a focus group we facilitated for the National

⁵⁸ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions*.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

⁵⁹ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions*.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

Disability Services⁶⁰ Zero Tolerance project, they linked this lack of preparedness and familiarity directly to their feelings of safety, and incidents of abuse and neglect.

Brendan: When I have new carers I feel a bit unsafe for a while but after that it's alright.

Facilitator: And is that because you don't know them, or they don't know you?

Brendan: Yes. Both. Like this bloke it was his first time supporting me I almost fell out the hoist...

Facilitator: Oh gosh.

Brendan: Things like that are frightening.

Facilitator: Ok. So what might help when you're feeling a bit unsure when you've got new support people? Is there something that the service providers could do to make that better?

Brendan: Tell the new workers how to support me.

Facilitator: Give them a good hand over?

Brendan: Yep that's what I mean.

Facilitator: How about you Kim, when there's new staff on – is there a way that they can find out how best to support you?

Kim: Yeah there is if they read the book but they often don't. But anyway I'd prefer it if they read but then also talk to me.

Facilitator: Yeah. So it's a bit about you not having to explain absolutely everything and they get some background knowledge-

Kim: Yeah but then if they've got an indication you can tell more stuff. And explain it a bit better or-

Brendan: -Yeah I might ask [supported accommodation agency] about that.

Facilitator: Would a new staff member whether they're a casual relief person or a new staff member do they get some hand over time? So maybe half an hour of time to read information and talk to you, talk to the other staff before they start working? Or when they walk in the door are they expected to start straight away?

Tim: Start work straight away.

Kim: It depends on what people [support workers] prefer. Some people will automatically would read. But others will use the time to do-you know if there's time. People make their own decisions about how they use it.

Brendan: I think it depends on how busy they are. They might have a bit of a handover but everybody's busy in the morning because all the people [residents] are going out.

(Focus group responses. Topic: safety in disability services)⁶¹

⁶⁰ NDS is the national peak body for disability support service providers

Solutions: preventing and responding to violence against people with disabilities

Accommodation

The separation of disability supports from provision of accommodation is central to deinstitutionalisation, and the NDIS paves the way to achieve this. However, the NDIS does not provide accommodation, and this means that as the NDIS rolls out some people will remain trapped in their current supported accommodation arrangements, with an expected wait of several years on the public housing list. This not only creates barriers for people with disabilities to escape violent situations, but it also encourages the conditions for violence to thrive because people with disabilities have no control and choice over their living arrangements, for example forced co-habitation, as outlined in Haley's case study on page 16. Affordable, accessible housing for people with disabilities must be resourced widely.

There is also a severe shortage of accessible emergency accommodation for people with disabilities. When a person with disability requires daily support with essential tasks, it is extremely difficult for them to flee a violent home environment to which their supports are attached, as is often the case in the pre-NDIS block funded system which remains in operation. Additionally, few crisis shelters and emergency accommodation options are built to universally accessible design principles.

Recommendation 9: Commonwealth to establish a plan targeted at increasing accessible, affordable housing for people with disabilities in the community, including public housing and crisis accommodation.

Recommendation 10: Commonwealth to fund a national audit of accessibility of crisis shelters/accommodation, including analysis of age, gender, racial, cultural and linguistic status, for people with disabilities, followed by proactive response to address the findings.

Access to justice

People with disabilities experience major barriers to accessing the justice system, from the point of reporting to police through to conviction or non-conviction of the perpetrator at court.⁶² At Advocacy for Inclusion, the issues faced by consumers include:

- General belief among service providers, government, and authorities that issues of violence, abuse and neglect should be dealt with by service providers, rather than by the justice system. This includes the police giving perpetrators warnings, and referring the issue back to the service provider to manage. The issue is often not understood as *violence* as it would be in other contexts, but rather is understood as a service problem.
- Domestic violence legislation does not recognise institutional settings as “domestic” in most states and territories, hindering access to appropriately targeted victim services, and encouraging services to perceive these matters as service issues rather than criminal justice matters.⁶³
- Belief among police that victims with disabilities are unreliable or are unable to endure a court proceeding, preventing them from charging perpetrators.

⁶¹ Advocacy for Inclusion facilitated a focus group to assist with National Disability Services' (NDS) Zero Tolerance Project. The Zero Tolerance report can be found here: <http://www.nds.org.au/projects/article/194>

⁶² Australian Human Rights Commission. (2014). *Equal before the law: Towards disability justice strategies*. <https://www.humanrights.gov.au/our-work/disability-rights/publications/equal-law>

⁶³ For example, the ACT Domestic Violence Crisis Service is not available to people with disabilities experiencing violence at home in a supported accommodation setting. In NSW DV legislation covers institutional settings for people with disabilities, and our colleagues in NSW tell us this has led to better responses by service providers and by government, including the funding of appropriately targeted programs and resources.

- Lack of accommodations and support for the communication and cognitive needs of people with disabilities throughout police and court processes.
- Victims with disabilities are dismissed as unreliable by the courts on the basis of their cognitive and communication impairments.

This lack of access and discrimination compounds the vulnerability of people with disabilities. It is a structural gap in Australia's justice systems, which invites perpetrators to target people with disabilities, knowing that the person with disability cannot easily access justice. A major overhaul of the criminal justice system is needed to address the discrimination and lack of access for people with disabilities, so that they are supported to respond to victimisation on an equal basis to people without disabilities. An example of how this could be achieved is the South Australian Disability Justice Plan, which is targeted at making the criminal justice system more accessible and responsive to the needs of people with disabilities. A plan like this is needed Australia wide, to ensure consistency, with genuine legislative and funding outcomes attached to it.

Recommendation 11: A National Disability Justice Plan should be established, with genuine funding and legislative initiatives attached, aimed at improving the accessibility of the criminal justice system for victims as well as offenders with disabilities. This must take into account intersecting factors such as age, gender, racial, cultural and linguistic status.

The role and challenges of disability advocacy

Advocacy by independent community based disability advocacy organisations, as funded under the National Disability Advocacy Program (NDAP), plays a vital role in preventing and supporting people with disabilities to respond to violence, abuse and neglect. Disability advocacy plays an important part in strengthening the voice of people with disabilities, who face extreme powerlessness in disability service settings, and also in providing independent outside scrutiny. At Advocacy for Inclusion, the connection with our organisation has often been the starting point for people with disabilities to speak up about violence against them, which they had not previously felt safe or entitled to disclose.

The *National Disability Strategy* recognises the significance of independent disability advocacy to rights protection for people with disabilities. However, disability advocacy is severely underfunded, unable to meet current demand, with the demand expected to at least double with the NDIS.^{64 65} Increased funding to match the increased demand for independent community based advocacy support is vital in helping to balance out power inequities, and offer a preventative as well as corrective mechanism at individual and systemic levels.

Individual advocacy

As demonstrated in Michelle's and Zafir's stories, individual advocacy provides one to one support to people with disabilities to respond to a range of issues, including violence, abuse and neglect in service settings. Individual advocacy support is provided with the person with disability's permission, and is focused on the expressed wishes and human rights of the person. Critically, this advocacy support is independent from disability support providers, which minimises conflict of interest. It provides direct, independent scrutiny of service providers, and it helps raise the voice of the person with disability who is often extremely powerless, and afraid of repercussions. Significantly, it provides support for people with disabilities to navigate and be heard in the criminal justice system, and advocacy for access to victim services, housing, and appropriate disability supports.

⁶⁴ DANA. (2012). *Independent Advocacy and the NDIS: A paper to consider the role of Independent Advocacy when there is a National Disability Insurance Scheme*. <http://www.dana.org.au/publications/submissions/>

⁶⁵ Productivity Commission. (2011). *Disability Care and Support*. Report no. 54, Canberra

Self-advocacy

Self-advocacy is about supporting people with disabilities to speak up on their own behalf, through learning about their rights and how to navigate the system. It provides a safe, informal and socially oriented space outside institutional settings, which emphasises the person's human rights and control by self-advocates over the group environment. Self-advocates form genuine friendships with each other in these environments. It also provides an avenue for people with disabilities to connect with formal services, such as counselling, sexual health and family planning, and recreational activities through information and referral provided by Advocacy for Inclusion staff helping to facilitate the group. For some, the group creates social connections that otherwise are not available to the person outside institutional supports, particularly for those who are isolated from family and other natural networks. This is critical in helping to reduce social isolation.

Systemic advocacy

Systemic advocacy identifies themes in issues raised by people with disabilities through direct individual and self-advocacy support, and feeds this back to government and non-government systems and structures (for example, through this submission). Advocacy organisations, as independent bodies, need to be funded to collect information about the experiences of people with disabilities out on the fringes, who otherwise are forgotten and silenced, and undertake direct consultation in ways that are accessible and meaningful to them so that this can have influence at the government and policy level.

Legal advocacy

Legal advocacy supports people with disabilities with the legal aspects of discrimination and other matters. This is highly important as many people with disabilities rely on service providers for a life-time and may encounter legal issues that are not covered by legal aid. Due to the economic disadvantage of people with disabilities they are also less able to afford legal representation not subsidised by government.

Recommendation 12: Commit extra ongoing funds to expand the capacity of the National Disability Advocacy Program at least equivalent to the funds provided to service providers and carer groups, ensuring that the full range of independent, community based disability advocacy is properly funded and made widely available.

Compliance burdens

The Department of Social Services has changed our external quality checking systems 3 times in the past 5 years, yet it cannot provide certainty about our funding. We have an extremely onerous compliance system of external annual audits. We are forced to spend thousands of dollars each year from our unindexed funding on auditors, which for Advocacy for Inclusion equated to 6 weeks' pay for a front line Individual Advocate this year. However, there is no funding support to keep up with the increasing demand for disability advocacy at this time of great change and reform.⁶⁶ This is a significant barrier to efficient and effective use of advocacy funding to promote the rights of some of the most marginalised members of the community.

Recommendation 13: Remove the onerous compliance burdens on the NDAP advocacy sector and redirect that money back into frontline advocacy.

The National Disability Insurance Scheme

The NDIS paves the way for people with disabilities to have more power over their support arrangements. It is critical in the movement toward full deinstitutionalisation, and in preventing violence, abuse and neglect of people with disabilities who have traditionally been at the total mercy of service providers. However, old attitudes and practices will continue for some time as the nation transitions to a new system. Support providers will continue to assume the management responsibilities in the new system, and people with disabilities will continue to face extreme powerlessness and therefore heightened risk of violence if this issue is not targeted.

⁶⁶ Advocacy for Inclusion. (2015). *Submission to the impact on service quality, efficiency and sustainability of recent Commonwealth community service tendering processes by the Department of Social Services.*
http://www.advocacyforinclusion.org/publications/Position_Papers/Senate_Inquiry_into_community_sector_funding_March2015.docx

The pre-NDIS system has also conditioned people with disabilities to take what little they are given in a grossly underfunded and unfair support system.⁶⁷

Independent community based disability advocacy plays a critical role in supporting this transition phase, by supporting individuals as well as providing feedback to government at the systemic level. People with disabilities need long-term support to build self-advocacy skills, and they also need independent individual advocacy support in the highly likely instance that regardless of their self-advocacy skills, other people continue to exert power over the person's life. For example, a number of our consumers who have undertaken the NDIS planning process have had pre-written contracts presented to them by their existing service providers, stipulating how they will receive services under the new regime. It is only because an individual advocate was present during the process that the person with disability was supported to effectively negotiate these contracts, rather than simply sign them and accept what was on offer (as they always have in the past in the previous system).

Although the NDIS will lead to much better outcomes for people with disabilities, and a more equitable distribution of power, access to independent advocacy remains vital in supporting people with disabilities to speak up when they are otherwise afraid of repercussions or simply not being listened to. It will remain important in helping to prevent violence by supporting people to achieve quality supports in the arrangement of their choosing, as well as in supporting people with disabilities who are victims of violence to find safety and navigate the justice system.

Independent statutory complaints body

An independent national statutory complaints and oversight body must be established to help balance out power inequalities and enhance accountability and transparency among service providers. This mechanism must be co-designed by people with disabilities.

It is well established in the research literature that when people are isolated, with a lack of outside scrutiny, they are at higher risk of victimisation and exploitation.⁶⁸ This coupled with the extreme powerlessness that people with disabilities can face in disability support arrangements creates a breeding ground for violence, abuse and neglect.

This complaints and oversight mechanism should apply to all disability services, regardless of whether they are funded by the NDIS, and consistently across all jurisdictions. It must also be available to people with disabilities in informal unpaid arrangements if the person with disability chooses, as currently applies under the ACT Official Visitor Scheme. It should have broad powers to investigate and enforce findings in regards to complaints, provider misconduct, violence, abuse and neglect against people with disabilities, which addresses the intersecting nature of these issues with other factors such as age, gender, racial, cultural and linguistic status.⁶⁹

Recommendation 14: A national independent statutory body for complaints, oversight and monitoring should be established and co-designed by people with disabilities. It should apply to all disability services, including all supports funded by NDIS, plus all other disability services regardless of funding source. It must also be available to people with disabilities in informal unpaid care arrangements as they choose. It must be independent from the NDIA and other services.

⁶⁷ Advocacy for Inclusion. (2013). *Ask me. I make my own decisions*.

http://www.advocacyforinclusion.org/images/Publications/Decision_Making/Control_and_Choice_Study_Report_FINAL.docx

⁶⁸ Marsland, D., Oakes, P. White, C. (2007). Abuse in care? The identification of early indicators of the abuse of people with learning difficulties in residential settings. *The Journal of Adult Protection*, 9(4), 6-20

⁶⁹ National Cross-Disability Alliance. (2014). *Senate Standing Committee on Finance and Public Administration: Inquiry into domestic violence in Australia: Joint submission from National Cross-Disability Disabled People's Organisations*.

Allegations of criminal activity against a person with disability should be reported and investigated by the police. Criminal activity in disability support arrangements is often perceived and dealt with as a service issue, and is kept out of the criminal justice system.⁷⁰ This encourages a high tolerance for crimes against people with disabilities in disability service settings.^{71 72 73} A statutory complaints body must not reinforce this by operating as a disability specific alternative to the criminal justice system. Rather, it must complement and work alongside the existing criminal justice system, offering additional supports, reporting and investigation mechanisms in acknowledgement of the extreme powerlessness, barriers to accessing help and justice, and high risk faced by people with disabilities in disability specific arrangements.

For example, if a person with disability reports a crime by an individual support worker to the police, the police should undertake their usual response to that report, as well as have the capacity to forward a report or information to the statutory body, which might then decide to conduct a broader investigation into the practices of that provider.

Recommendation 15: The statutory body should complement and work in collaboration with the existing legal structures, such as the police, in recognition of the extreme powerlessness faced by people with disabilities due to societal inequalities, and their subsequent increased risk of victimisation and exploitation. It must NOT operate as a disability specific alternative to the existing justice systems.

A streamlined national community visitor scheme should be delivered by the statutory body. The purpose of this body should NOT be to operate as an adult protection system imposed on people with disabilities, which can further disempower and discourage people with disabilities from seeking or accepting help. It must be based on the protection of individual's rights and expressed wishes. It must be properly funded and resourced, easy to access and readily available to people with disabilities. While it should not have the capacity to impose on people with disabilities, it should have authentic statutory powers to investigate with or without service provider consent.

Recommendation 16: The statutory body must be fundamentally focused on protecting the rights, will and preferences of people with disabilities. It must be imposed on providers of support, NOT on people with disabilities.

Recommendation 17: The statutory body should have broad and authentic powers to investigate and enforce findings in regards to information and complaints received by people with disabilities, community members, and other statutory systems.

Recommendation 18: The statutory body should be funded in order to meet the demand and access needs of people with disabilities. It should be allocated a fixed percentage of all other disability related spending

Recommendation 19: The statutory body should include a national community visitor scheme as part of its function.

Critically, this oversight body should collect data disaggregated by age, gender, disability status, place of residence and cultural background, as per international obligations and recommendations by UN treaty monitoring bodies.⁷⁴ This is critical in understanding the issues occurring for people with disabilities in their

⁷⁰ National Cross-Disability Alliance. (2014). *As above*.

⁷¹ Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

⁷² Jenkins, R. Davies, R., & Northway, R. (2007). Zero tolerance of abuse of people with intellectual disabilities: Implications for nursing. *Journal of Clinical Nursing*, 17, 3041-3049.

⁷³ Strand, M. L., Benzein, E., & Saveman, B. (2004). Violence in the care of adult persons with intellectual disabilities. *Journal of Clinical Nursing*, 13, 506-514.

⁷⁴ UN Committee on the Rights of Persons with Disabilities. (2013). *Concluding observations on the initial report of Australia*. http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUS%2fCO%2f1&Lang=en

support arrangements, developing policies and legislation that enable people with disabilities to access basic human rights, and to monitor progress.

Recommendation 20: The statutory body must address the intersecting nature of disadvantage among people with disabilities, including factors such as age, gender, racial, cultural and linguistic status. This includes collection of data disaggregated by age, gender, racial, cultural and linguistic status, and living arrangement to understand the issues and monitor improvements in accordance with the UN CRPD.

Difference between NDAP funded advocacy and a statutory body

An independent statutory complaints body meets different needs to that met by independent community based disability advocacy. Community based disability advocacy (as provided under the National Disability Advocacy Program) is less formal and does not have statutory powers attached to it.

NDAP advocacy organisations provide the types of advocacy support that can be engaged before complaints arise as well as in response to issues. They are available to provide practical navigation and advocacy support to individuals. For example, an Individual Advocate can provide a person with disability support through the NDIS planning process, to ensure the person's wishes are heard and respected, and to help avoid the person being overpowered by other stakeholders and therefore issues arising in the delivery of support after the plan is made.⁷⁵ In comparison, a statutory body would be focused on receiving complaints and providing oversight and monitoring.

⁷⁵ Advocacy for Inclusion. (2014). *Enhanced self-advocacy group project report*. Retrieved from http://www.advocacyforinclusion.org/publications/Reports/Enhanced_Self-Advocacy_Group_Report_FINAL.docx

Conclusion

Although violence, abuse and neglect also happens against people with disabilities in the general community, such as in private homes and mainstream schools, the institutional nature of disability specific settings acts as an incubator for violence. The idea that institutions protect people with disabilities is a common and dangerous misconception. Although traditional large scale institutions have almost disappeared from the Australian landscape, institutional practices have been carried over to contemporary disability support systems and contexts. All institutional models of support, including respite houses, smaller group homes, day centres, sheltered workshops, special schools etc – are inherently flawed and must be phased out.

The NDIS brings new opportunities to finish the process of deinstitutionalisation that began decades ago, because it provides support attached to people with disabilities as they go about their lives in the general community. However, true deinstitutionalisation requires a significant amount of work outside of the NDIS to enable real inclusion. This includes broader structural change such as better access to the justice system, community resources, education, housing, and employment, to lift the status of people with disabilities. Without opportunities equal to that of the general population, people with disabilities will continue to find themselves forced into living, support, and work arrangements, with no choice and control. They will continue to face powerlessness and therefore remain at heightened risk of violence, abuse and neglect.

Oversight and accountability mechanisms, such as a statutory complaints body, and community based disability advocacy are vital in helping to balance out power inequalities, and to support people with disabilities to have their voices heard in a context that is currently extremely inequitable and challenging.

Importantly, a thorough national investigation into violence against people with disabilities in institutional settings is a priority concern, which due to the complexity of the issue could only be achieved by a Royal Commission. The Committee undertaking this inquiry has faced a number of hurdles in creating an accessible and adequate Inquiry due to the nature of the matter at hand, and we fear the vast majority of people with disabilities in institutional settings will not have been reached by the investigation. A Royal Commission would enable a desperately needed deep analysis; a structured capacity to reach out to the people it seeks to hear from, better measures for accountability of services and individual perpetrators, and robust scrutiny into this widespread yet mostly hidden problem.