



Action for More Independence & Dignity in Accommodation

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Advocacy, Self Advocacy, Rights, Accessibility, & Community Living for People with a Disability

A Submission to the Family and Community Development Committee — for the inquiry into abuse in disability services.

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AMIDA is funded in part by the Australian Government's National Disability Advocacy Program through which agencies across Australia provide people with disabilities access to effective, independent disability advocacy that promotes, protects and ensures their full and equal enjoyment of all human rights enabling full community participation.

This funding, and that provided by the State government under the National Framework for advocacy, means that people of all ages with disability can receive advocacy support from one of these agencies free of charge.

Everyone deserves to have their voice heard, their rights upheld and the power to make their own choices and decisions over matters that affect their lives. To support this right, AMIDA provides individual advocacy, self-advocacy support, family advocacy support and systemic advocacy.

In any discussion of addressing abuse and its prevention and reporting, the provision of advocacy support must be considered as part of the safeguarding framework. It is vital advocacy funding continue and expand during and after the transition to the NDIS. AMIDA is also the lead agency in the consortium managing the State funded Self Advocacy Resource Unit. The growth of self advocacy over the last six years has been an important development in peer support, safe places for discussion of rights and safeguarding against abuse and it must continue to be supported and expanded.

In the course of our work over 30 years we have had involvement with a numerous cases and wish to contribute our observations and analysis. We will also raise some important examples of advocacy provision that help prevent and identify abuse.

(a) in particular the inquiry will include but not be limited to:

(i) why abuse is not reported or acted upon;

Many disabled people can speak up for themselves to complain, report abuse and get access to an advocate but not everyone can and there are significant barriers such as cognitive ability and communication impairment. However the most disabling factor preventing the reporting of abuse is the control paid carers and disability services have over clients and their vulnerability given the

likelihood that perpetrators of abuse are also the providers of needed daily support. There is legitimate fear of reprisals held by clients of disability services. The reprisals can include further abuse, restrictive practices, lack of choice in the house or lack of involvement in decision making over matters affecting the person. Other negative reprisals may be withdrawal of favoured activities, lack of support in a timely way, restriction of meals etc. Reprisals can also be quite subtle such as unpleasant mood or tone of voice of the carer or lack of attention in general given by the carer to the client (cold shoulder treatment).

People become institutionalised by this manipulative treatment and often try to predict what the carer wants them to say or choose, so as to avoid negative consequences. Even good workers and services find that clients are reluctant to complain and prefer to please. In disability services the power to decide often lays with the service provider because of duty of care. This power is understood by clients. A culture of control, dominance by single service providers, isolation, lack of frequent independent oversight, lack of access to advocates or other community members has been a feature of disability services. There cannot be too much independent oversight to counter this and while registration and quality standards checking will help it is only quite recent and practices are entrenched. Isolation of people with a disability in residential and day services compounds this culture and control.

(ii) how it can be prevented;

1. AMIDA was funded a small amount by DHS of \$30,000 per year for two years to provide information peer to peer training to residents in shared supported accommodation about their rights in the service including their right to be free of threats, harassment, bullying, violence and abuse. In the course of going out to 86 different houses we had numerous instances of abuse disclosed to us and were able to advocate for the individuals to remedy the situations.

The funding we received was used to provide accessible information and face to face training to residents which provided many with an opportunity to discuss abuse with advocates. This had never happened for any of them before. Most people with a disability in shared supported accommodation live lives closely controlled and influenced by services providers who have a vested interest in complaints not being made. AMIDA found it extremely difficult to access these properties because of service provider resistance and worked hard to be able to do so. These services were able to hide behind standards of privacy as the residents addresses could not be provided to AMIDA. When we did have our information delivered to houses via a middle manager, we had no confidence the residents actually received the information or were told of our wish to visit them.

Unfortunately the funding was of a one off nature and we have not been refunded despite requests to DHS and the Office for Disability and support for the project from Office of the Public Advocate and reports from Disability Services Commissioner that say this type of peer education program actually prevents as well as reveals abuse. There are 1000 shared supported accommodation homes in Victoria with around 6000 residents and we were only able to visit 86 houses. In so doing we were made aware of numerous cases of abuse that had not been reported to community visitors or anyone else.

This is because we had time without staff present where we provided information specific to rights, presented by people with a disability and in a very accessible way that people understood. We

made repeat visits and people trusted us as advocates who were independent and would help them. We support the Community Visitors program as another independent source of monitoring disability services. While Community Visitors can observe and report on practices in residential services they are not able to be partisan. Advocacy is partisan and we state we are clearly on the side of the residents. Our, 'Know Your Rights' education program provided a context for explaining what rights and abuse are, followed by discussion of residents experience of rights and abuse. Residents told us about abuse because no-one had ever come to them and explained what abuse was and talked to them about rights and abuse before. We provided a safe opportunity to talk about rights and abuse with peers which is unlike any they had previously had. **Our concern is, if this type of peer rights training and discussion is not provided, many people with a disability will never have the opportunity to safely report abuse and so abuse will go unreported.**

(i) Stage 1:

(A) *the Committee should consider the strengths and weaknesses of Victoria's regulation of the disability service system with a view to informing Victoria's position on appropriate quality and safeguards for the National Disability Insurance Scheme, this may include issues being considered for the quality and safeguards framework including:*

(I) *workforce recruitment, screening, induction, training and supervision;*

AMIDA supports the current Victorian DHHS worker safety screening requirements. The NDIS must incorporate Police check, Working with Children Check (if relevant to the role), a check against the Disability Worker Exclusion List, a Disqualified Carer Check, Employment History Check (including disciplinary action disclosure and checks of qualification and training). This is vital to ensure the safety of people with disability.

Training, induction and supervision are vital and yet the standards expected are not high enough in AMIDA's view. In our experience it is difficult to substantiate claims of abuse when workers are on shifts alone. As much as possible sole workers should be discouraged. This will act to prevent abuse as well as it removes the opportunity to abuse.

While it is good that in some cases the workers complained are moved away from direct contact with our clients, it is concerning that often they are still working with other vulnerable people while these matters were being investigated. Internal service investigations differ and there is not always suspension of the alleged perpetrator, nor is there guaranteed shadowing of this worker while they continued to work with other vulnerable clients.

Even though the complaints of abuse are often found to be unsubstantiated because no one else witnessed the alleged abuse, the complaints were not disproved and it is possible that the alleged abuse did in fact take place and the perpetrators are still working with vulnerable people. This is extremely concerning. Many encounters between staff and people with a disability happen without other witnesses. This is sometimes to maintain client privacy but is also due to lack of adequate resources to employ more staffing who could monitor each other. Even in shared spaces in residential services there may only be one staff member working with a number of clients and no other monitoring by staff of what is taking place.

There is also pressure put by staff on each other and residents to not write up or talk about incidents that occur. Bullying and a culture of "don't dob in your mates", is a problem for monitoring and reporting abuse and neglect. There is a need for more training of new and existing staff to counter attitudes that allow unnecessary restrictions and abuse to go unreported.

Incident Reporting as a form of monitoring.

DHHS has a thorough process of incident reporting and handling. Improvement can and should be made and the Victorian Ombudsman is currently reviewing this system. It is different from complaints handling but equally as vital and has been neglected in the consultation paper on a Quality Safeguards System under the NDIS by DSS. The Victorian approach to incident reporting is worth highlighting and should be emphasized in any negotiations around the NDIS.

AMIDA believes the Victorian system of incident reporting could be adopted nationally if improved in a couple of key ways. Sequential numbering of incident reports does not currently happen at the service level only once reports have been forwarded to DHHS. So, for example, if a report is missing from the sequenced pages in a residential service this absence cannot currently be noted. Presently Community Visitors who have access to house records cannot detect if initial incident reports have been destroyed. Also incidents are categorized according to seriousness but only the highest categories have to be reported to the funding body. All incidents of harm need to be acknowledged and acted on so all incidents should be reportable to either the funding body or an Independent Complaints Body. Incident Reporting is vital because people with a disability usually don't or can't complain.

(II) provider registration requirements;

AMIDA supports mandated participation in an external quality assurance system for providers of supports. Presently, the Quality Audits against the National Standards for Disability Services are a thorough, independent way to assess services. Within the audit there are reportable actions. AMIDA has grave concern that if thorough, independent audit is not carried out and continued, then poor/bad practices will not be discovered and corrected. Systematic audits including reportable actions must be incorporated into the NDIS to ensure regular checks of service provision to people with disability. The present audits have ensured our service has improved its practices, and continues to do so.

Current practice is that Auditors refer instances of non-compliance or reportable incidents to DHHS in Victoria and the funding body works with services to bring them up to acceptable levels. The Auditor is somewhat limited in their ability to continue working with services to get improvement. NDIS should take on this role so people with disability have consistent services.

The right balance between providing assurances and allowing people to confidently raise issues of concern can be achieved with the support of independent advocacy services which can provide information and support to people with disabilities wanting to complain and participate in audits

Safeguards for participants who manage their own plans

Ideally everyone wanting to provide services can register with NDIS in future. People with disability are vulnerable, and therefore, even if managing their own plans, people with disability must be protected.

We do agree to providing people with support to build capacity to manage staff selection. Resources, for example on risks and checklists to ask about and the pros and cons of choosing a registered provider must be available.

If people are managing their own support, they may require advocacy at some stage. This independent, free service must be available to them.

(III) systems for handling complaints;

Complaints Handling

An Independent Disability Complaints office is the best option that would provide the safeguards that people with disability require in the transition to NDIS. An independent body to oversee complaints is vital. It must also have investigatory powers and be willing to use them. If the Independent Disability Complaints office is established it should have at least all the current roles of the Disability Services Commissioner such as compiling of complaints made directly to service providers.

The complaints body must have the power to not only investigate complaints, but to require changes and adjustments to disability services which are found to be in contravention of human rights, legislation and regulation.

As the NDIS rolls out around Australia it must be acknowledged that Victoria has traditionally had strong safeguards, with accompanying opportunities for complaint, ie, the creation of the Office of the Disability Services Commissioner, Office of the Public Advocate, Senior Practitioners Office and the Ombudsman. These offices presently accept complaints about disability services, and investigate, and recommend liaison with service providers by users. They also provide advice and suggestions for improving relations between users of services and service providers. If this is not the case in other states, then it must be ensured that other states are required to set up similar bodies to bring them into line with Victoria. Victorian standards must not be lowered to bring them into line with systems with lesser safeguards in place.

Support to Complain

Nevertheless just having a place to complain is not enough. People with disability must be continually encouraged to complain where necessary and be supported to do so. Only then will the extent of injustice and inequality be exposed and quality in disability services be improved.

Advocacy organisations can support people with disabilities to make complaints and follow them up.

Advocacy can provide education and also follow up complaints directly with service providers and/or formally to an independent body like the Office for the Disability Services Commissioner or the Ombudsman.

An additional obstacle to people with disability making complaints is that people are often reluctant to complain for fear there will be repercussions, or they have been unsuccessful in previous complaints and are worn down by previous endeavors. A major component of a complaints handling system must be the availability of disability advocacy.

Further, we must also ask why service providers don't invite advocacy. AMIDA's experience is that it is difficult to gain entry to group homes, work places or day services to deliver information that people with disability need. Approaches are made to all these services, and instead of welcoming the opportunity for information to be made available for the people they work with, services are defensive of any criticism of their service or proposals for improvements that will benefit people with disabilities. We have seen with the Royal Commission into Institutional Abuse that organisations have a tendency to defend the organizations interests at the expense of the victim of abuse. We must acknowledge this tendency and introduce additional safeguards around access of advocacy in all services. Advocacy should have a right of entry to all disability services in order to offer our advocacy support directly to service users rather than have to go through service providers with a vested interest in excluding us.

Legislative right to enter services should be created to allow advocacy services to come in and offer to provide people with information about their rights. Services cite privacy concerns when they refuse to give addresses of residential services. Services must give right of entry to advocacy services who can directly ask clients if they want information, and they must allow a mailing house intermediary to have the addresses in order to supply people with disability with independent

rights information and information about advocacy services, self advocacy and self advocacy groups.

Complaint as opportunity for improvement

In our service we see complaints, self assessments and audits as a way to improve the service we provide for people with disabilities. It must be written into the NDIS Safeguards & Framework System as a matter of course, that complaints and suggestions should be seen as opportunity. In this way services may change the way they see advocacy, advocates, self advocates and self advocacy groups. This will be a benefit to all in the disability field, ie people with disabilities, families, service providers and workers.

The Victorian government should support a new NDIS complaints system which should cover all supports funded by NDIS and provided to people with disability, regardless of whether the services are registered with NDIS or not. In this way, it can be assured that supports to people with disability are monitored, safe and accountable. It will be in the interests of unregistered support providers to comply with this complaints process or the person may choose another provider. Given the experience and understanding of disability support, this Independent Complaints Office will be superior to Consumer Affairs Complaints processes.

Incident Reporting is as previously discussed is also vital because people with a disability usually don't or can't complain but observed incidents can be recorded and investigated.

Broad investigations

Some large service providers are now contracting out investigations of abuse. We have no guarantee that the investigations carried out internally by services or by independent investigators they contracted were broad enough. Other staff or clients may not have been asked about their experience of the alleged perpetrator but may have had vital information they had not shared because of their vulnerable situation and or difficulty communicating. Given the vulnerability of people with a disability the investigations should be broad to "door knock" other potential witnesses or similar experiences including from other clients and staff. While confidentiality of the complainant must be maintained if they wish it, this should not be used as an obstruction to a thorough investigation. A properly empowered Complaint handling and investigation service would be preferable to privately contracted agencies currently doing this work.

Independence and freedom from conflict of interest

Independent investigation and freedom from conflict of interest is vital. However the independent investigators from a private company do their investigation for the service provider and reported findings to the service provider. The client is the service provider.

The Disability Services Commissioner has the power to investigate allegations and reports of abuse but has not conducted any investigations. They operate primarily as a mediator and educator and while this has value there is a desperate need for independent investigation of reports of abuse and they are empowered to do so yet choose not to.

Accountability and Responsiveness of services

Internal responses by service providers to complaints of abuse and neglect often are defensive and seek to protect the organization. Information isn't always provided to families about incidents and they don't know these reports exist. Much documentation can be missing as there is no

numbering of incidents at the house level and they can quite easily be destroyed without trace. They are only numbered when they reach the level of being reported to DHHS.

Services know that users of shared supported accommodation have no choice to shop around for these services as they are in great demand and vacancies are managed by DHHS on a crisis driven system. Because service users do not have the option of simply leaving and easily acquiring another service, providers have no motivation to keep service users choosing their service.

In our experience, services and their workers don't always ask themselves first whether actions they take are respecting people's human rights, are least restrictive and are best practice. Many do what is convenient given the demands placed on them and operate from a position of power over clients. They operate free from scrutiny most of the time and collude with each other to reduce threats to themselves. It is extremely rare that any service provider has ceased or lost funding because of abuse or even poor management of its aftermath.

Timely and “disability aware” investigations

Police investigation of reported abuse is done at the local police station where it is reported and the response seems very ad hoc in our experience. Police did not understand the need to communicate with the advocate even when they had difficulty contacting the client directly and despite this need being made clear when the report was made. In one case the time taken by the investigation was such that the memory deficits the client had led to them being no longer confident and withdrawing the complaint.

Because of the power workers have in the lives of people with a disability there are barriers to people with a disability expressing their own view. It is not uncommon for people to agree with whatever workers say, because they are workers and clients are vulnerable and want to please. While on the one hand reporting back to clients what the worker has said which contradict the complaint can give the complainant a chance to respond, it also introduces another challenge for the complainant to overcome and may subtly put pressure on them to withdraw the complaint.

Accessing Advocacy

Service providers don't always refer people with advocacy needs to independent advocacy services. When a client makes a complaint about abuse they should be made aware of advocacy services and referred to these if they wish. Where advocacy is provided their involvement must not be controlled by the service provider but be managed by the independent investigator to ensure they are able to assist at all stages of the investigation.

Advocacy provision must be guaranteed for those who request this. The provision of advocacy is reliant on funding to organisations that are independent of disability service providers. This independence and funding must be maintained. Funding must be increased if independent advocacy is to be available to all those victims of abuse needing and seeking advocacy.

(IV) the impact of current systemic safeguards on the rights and protections of people accessing disability services;

Reducing and eliminating restrictive practices in future NDIS funded supports

Many of the issues and complaints that come to AMIDA are about restrictive practices in group homes. Instead of group homes being an improvement on large scale institutions, we see the

same problems and issues that were once present in institutions before deinstitutionalisation. Examples of restrictive practices and their impact on people with disabilities are:

- Restrictive practices on one person are impacting on other people in the house, eg dietary requirements for a couple of clients are imposed on all.
- Staff convenience takes precedence - to the detriment of people living there.
- What is often seen as normal is in fact restrictive, eg locked doors, cupboards, early meal and bed times, grouped activities at the expense of individual activities.
- Services are set up to reduce risk and 'unconsciously' and unnecessarily restrict those living in the house.

Restrictive practices are a risk factor in abuse as they deny freedoms and if not warranted is a form of abuse. If restrictive practices are recommended or practised, then there must be strict supervision/reporting of these practices, and of course restrictive practices must only be used as a last resort. Restrictive practices should only be authorised by an independent decision maker resourced in alternatives, such as the Senior Practitioner.

Application for Restrictive Practices must not simply be rubber stamped. Review and alternatives should be shown to have been explored first.

There needs to be a mechanism to appeal decisions.

Reporting of Restrictive Practices

In Victoria the Senior Practitioners Office is a worthy model for overseeing restrictive practices. However AMIDA is aware of practices which are not reported, as they are not acknowledged as restrictive. An example is one resident being restricted with food, as others in the household are on special diets, and 'it is difficult to give people something different'. This restriction is having a huge impact on this particular person's health and wellbeing, and he is in fact being restricted, without it being considered as a restrictive practice. If the restriction isn't identified by the service provider, authorization isn't sought. More education of what constitutes restrictive practices is needed throughout disability services.

AMIDA supports mandatory reporting on the use of restrictive practices to safeguard people's human rights.

The Senior Practitioner's Office in Victoria has been proactively providing services with alternatives to restrictive practices and we believe this model could with modifications work on a national level.

Are current safeguards enough?

While the current systemic safeguards on the rights and protections of people accessing disability services in Victoria are of merit their impact does not prevent abuse. More frequent visits by community visitors are needed. Right of access for self advocacy and advocacy group members who are funded to educate and discuss rights and abuse in a safe setting and provide follow up support is needed. More investigations by the Disability Services Commissioner are needed rather than just mediation and conciliation. More education on what constitutes restrictive practices is needed in services.

Part of the problem in shared supported accommodation is systemic. Over-clustering of clients means that residents sometimes abuse and assault each other. Grouping residents is a way of saving on the cost of staffing and additional properties. However houses started with 3 and 4 residents and now are usually 5 or 6 and up to 9. The combination of personalities is increased as resident numbers increases and the likelihood that some people won't get along also increases. The staff to resident ratio is increased so staff has less time to spend with each individual. The likelihood that routines and institutional practices will be used also increases as staff struggle to cater for more people. With the increased funding coming from the NDIS Victoria should use the opportunity to decrease the resident conflict in properties by reconfiguring them so there are smaller units within properties. This will require staffing to be in each separate area and increase the staff to resident ratio. As much as possible staff should not work alone with residents as this allows staff to monitor each other, provide a disincentive to abuse and a potential witness to abuse, apart from the victim. Again the increase NDIS funding may assist.

The safeguards cannot on their own challenge a culture of control, dominance by single service providers, lack of choice of service provider and isolation of service users. However, increasing the strength of safeguards such as more frequent independent oversight, access to advocates or other community members will begin to open services up to change. There cannot be too much independent oversight to counter this culture of control and while registration and quality standards checking will help it is only quite recent and practices are entrenched. Isolation of people with a disability in residential and day services compounds this culture and control. Much more training on rights and abuse is required in disability services for staff and service users.

We have seen with the Royal Commission into Institutional Abuse that organisations have a tendency to defend the organisations interests at the expense of the victims of abuse. We must acknowledge this tendency and introduce additional safeguards around right to access of advocacy in all registered disability services. Service users should have the right to hear our offer of advocacy support directly rather than through service providers with a vested interest in avoiding stirring up complaints.



Pauline Williams

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