



**Carers Victoria submission
Victorian Ombudsman investigation into how allegations of
abuse in the disability sector are reported and investigated**

Carers Victoria

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About Carers Victoria

Carers Victoria is the state-wide peak organisation representing those who provide care. We represent more than 700,000 family carers across Victoria – people caring for a person with a disability, mental illness, chronic health issue or someone with an age-related condition. The people being cared for could be a parent, child, spouse, grandparent or a friend.

Carers Victoria is a member of the National Network of Carers Associations, as well as the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership-based organisation. Our members primarily consist of family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

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1. Carers Victoria summary of recommendations

Carers Victoria presents the following recommendations for consideration by the Victorian Ombudsman during the investigation:

1. The impact of abuse in the disability sector is considered with recognition of the interdependence and interrelatedness of the lives of people with disability and their family carers.
2. The investigation adopts a broad definition of abuse that goes beyond the legal definition of assault.
3. All reports of abuse are taken seriously by disability service providers and police, including those made by family carers. Regardless of any police action, disability service providers should be required to appropriately investigate, and respond to, all reports of abuse.
4. Appropriate supports such as information, counselling, validation and emotional support be provided to family carers while they are supporting people with disability who has experienced abuse.
5. Development of clear information in plain English about the steps that will be followed by the service provider after a complaint is made, including how and when feedback will be provided to the person with disability and their family carers.
6. Careful consideration be given to the balance of safeguarding risk with increased choice and control as Australia moves towards consumer directed models of disability service delivery.

2. Introduction

Carers Victoria welcomes the Victorian Ombudsman's investigation into how allegations of abuse in the disability sector are reported and investigated. As the Ombudsman has identified, the available data demonstrates there are deficiencies in the way allegations of abuse in the disability sector are reported and investigated, including communication with families and carers¹.

Abuse of people with disability affects the entire caring family². Carers Victoria suggests the Ombudsman considers the impact of abuse in the disability sector with recognition of the interdependence and interrelatedness of the lives of people with disability and their family carers. The impact of abuse is experienced by both the person with disability and their family carers. The impact can be significant, long-lasting and lead to deep mistrust of the disability service system.

Carers Victoria has encouraged carers across Victoria to make submissions directly to the Ombudsman, particularly if they have had experience of reporting abuse, to assist the Ombudsman in understanding the carer experience in this area.

3. A profile of carers in Victoria

Carers provide unpaid care and support to a family member or friend needing assistance with a disability, mental illness, chronic health condition or age-related frailty. Carers come from all walks of life, across all age groups and all cultures. Not all carers identify themselves as carers, and may instead identify themselves in terms of their family and friend relationships.

There are an estimated 773,400 informal carers in Victoria, which is 13.6% of the Victorian population. Of these, 217,800 (3.8% of the Victorian population) are primary carers, defined as providing the majority of ongoing care to the person requiring assistance³.

4. Defining abuse

The definition of abuse that will be used during the Ombudsman's investigation has not been specified. Abuse can be broadly defined and goes beyond the legal definition of assault. Abuse includes physical, sexual, verbal, psychological or emotional abuse, constraints and restrictive practices, financial, legal, civil and systemic abuse. Carers Victoria suggests the investigation adopts the broad definition of abuse that goes beyond the legal definition of assault.

Abuse in the disability sector can reference staff to client⁴ abuse, but abuse can occur between clients while in the disability service setting. Clients and family carers can also

¹ Victorian Ombudsman (2015) Media Release - VO to investigate disability abuse reporting.

² The terms 'carers', 'family carers' and 'caring family/ies' used in this submission includes the diverse range of people in care relationships, including carers and people receiving care in same-sex families, 'families of choice', friends and others who provide unpaid care.

³ Australian Bureau of Statistics (2013) *2012 Survey of Disability, Ageing and Carers*, Cat. No. 4430.0.

⁴ The term 'client' is used to refer to a person with disability who is receiving disability services, as this term is used in the literature and research for this subject.

witness or become aware of abuse of the person they care for, as well as other clients of a service. All of these situations raise questions about how allegations of abuse in the disability sector are defined, acknowledged, reported and investigated.

5. The role of carers in safeguarding and reporting abuse

Caring families hold a vital role in raising concerns and reporting abuse of the people they care for when they are receiving disability services. A Disability Services Commission (DSC) report⁵ states that around half of all enquiries and complaints to the DSC are made by families. While the DSC report addresses complaints more broadly, it is of relevance to reports of abuse. The DSC reported⁶ that the majority of complaints are about services provided to people with an intellectual disability. The DSC's experience is that many people with an intellectual disability need support and rely upon others such as family members to speak up about their concerns about services and supports they are receiving.

Carers Victoria recommends all reports of abuse are taken seriously by disability service providers and police, including those made by family carers. Regardless of any police action, disability service providers should be required to appropriately investigate, and respond to, all reports of abuse.

While the DSC has reported an increase in the number of complaints in recent years, the DSC believe many people with a disability and their families are still afraid to voice their concerns, due to fear of retribution and loss of services or relationships. This finding reflects the concerns raised by carers during the broad range of interactions Carers Victoria has had with carers over time, including through a range of carer consultations on various issues affecting carers.

Carers Victoria believes that carers can be required to hold an important role in safeguarding the people they care for from abuse; however carers are not always supported in this role. Relevant themes from carer consultations undertaken by Carers Victoria support the key findings from the literature and research⁷; and are as follows:

- Abuse experienced when accessing disability services has profound and long-lasting consequences for the person with disability and the caring family. The trauma can be life long, remain unresolved and lead to deep distrust of the disability service sector.
- Qualifying for, and accessing disability services can be extremely difficult, and these services can provide much needed support and assistance to carers in their caring roles. Even when a suitable service has been accessed, changes can occur that affect either the access to, or the quality of, the service being received. Staff changes, turnover, inadequate staff training and inappropriate staff recruitment are of particular concern to carers. Carers believe that service providers have too much scope and freedom to make these kinds of significant changes to service delivery (e.g. reductions in staff, service hours or transport assistance), and are not required to justify these changes to clients, their families and governing bodies. These

⁵ Disability Services Commissioner (2014) *Families and service providers working together*, Learning from Complaints, Occasional Paper No. 2.

⁶ *ibid.*

⁷ See literature reviews in Disability Services Commissioner (2012) *Safeguarding People's Right to be Free from Abuse*, Learning from Complaints, Occasional Paper No. 1.

service changes can affect both the person with disability and their family carer with resulting impacts flowing through to their caring role.

- Carers advise that they believe some service providers are not held adequately accountable for gaps or shortfalls in service provision. These gaps in service provision can increase family carers' role as they try to meet the shortfall. As a result, carers would like governing bodies to invest greater resources and measures in monitoring service providers and their service provision, including ensuring that any recommendations resulting from complaints in this area are implemented and sustained.
- Carers are concerned that if they complain there will be a resulting impact on the services received and/or consequences for the staff involved, such as causing a worker to be terminated. Carers do not know what will happen as a result of making a complaint and this can lead to them withdrawing the person they care for from a service rather than entering into a complaints process. As a result, carers feel powerless, and the complaints process can be intimidating. The impact on the carer who may need to or chooses to increase their caring role as a result of their concerns about the complaint process can be significant, reducing their own health and wellbeing.
- Carers do not always feel included in the complaints process. Some carers who have raised complaints regarding the person they care for felt they did not receive adequate communication and information throughout the complaint process and in some cases believed that key information was concealed.
- Some carers who have raised complaints with service providers have felt unacknowledged or dismissed as overly paternalistic or 'overprotective', or felt coerced into accepting what they believe is an unsatisfactory outcome.
- Carers state that some service providers do not provide adequate support to the person they are caring for to manage the complaint process and aftermath, both at a practical level and at an emotional level. Carers have reported that within some complaint processes, the person receiving care is given the responsibility of articulating and representing themselves, even though they may not have the resources or capacity to do so independently.
- When carers have concerns about the quality of services the person they are caring for is receiving and the potential for abuse in these services they may respond by:
 - Choosing not return to that service.
 - Feeling pressured or obligated to take on the role or function of the service themselves, sometimes to the detriment of their own health or wellbeing.
 - Becoming stressed about the wellbeing or safety of the person receiving care if they feel a lack of confidence in, or mistrust, the service providers. This leads to some carers adopting the responsibility of closely monitoring the service being received by the person they are caring for. This can create tension between the carer and service provider.

6. Supporting carers

Literature and research⁸ concerning abuse of people with disability highlight the importance of recognising and supporting the 'informal safeguards' of families and friends. Carers Victoria supports this approach and includes family and friend carers within this network of safeguards. Carers Victoria welcomes the explicit recognition in documents such as the Office of the Public Advocate 'Inter-agency guideline for responding to the abuse and neglect of at-risk adults' (IGUANA), of the need to support

⁸ A summary of the literature is contained in the Disability Services Commissioner (2012) *Safeguarding People's Right to be Free from Abuse*, Learning from Complaints: Occasional Paper No 1.

the person with disability who has been subjected to abuse by engaging with the family and other supports.

However, Carers Victoria believes there is a gap in the existing documentation and support services for those family members and carers who either choose to, or are expected to, have a support role following abuse, whether this abuse is reported or not. Specifically, there is a lack of resources to assist carers take on a support role after abuse, and during an abuse investigation. Providing support to a person with disability who has been subjected to abuse can be traumatic and stressful, and Carers Victoria recommends that appropriate supports such as information, counselling, validation and emotional support be provided to carers while they are undertaking this role.

Improving the transparency of the steps in the complaints process would also assist carers and the people they care for in coming forward to make complaints, including reporting abuse. Carers Victoria recommends the development of clear information in plain English about the steps that will be followed by the service provider after a complaint is made, including how and when feedback will be provided to the person with disability and their family carers. This would assist in addressing the existing uncertainty and concerns about making a complaint and likely outcomes at each step of the process.

The role of Carers Victoria

Carers Victoria supports caring families through information, online and face to face training and education programs, respite support, counselling and systemic advocacy. In 2013-14 Carers Victoria had 28,545 interactions with carers through our carer advisory line, counselling and other support services.

When accessing support services provided by Carers Victoria a carer may raise concerns or experiences of abuse against the person they are caring for, or other clients, while they were receiving services in the disability sector. If this occurs there are a range of supports Carers Victoria will provide to the carer, depending on the carer's situation, experience and wishes. Some experiences of abuse raised by carers when receiving support services from Carers Victoria can be many years or even decades old. Carers Victoria will provide appropriate support for each situation, which may include emotional support, validation, assistance and education. Where appropriate, Carers Victoria will also provide referrals to the Victorian Police, or complaint and advocacy services such as the Disability Services Commissioner (DSC).

7. Transitioning to the NDIS – safeguarding risk

Another area Carers Victoria would like to raise for consideration by the Ombudsman as part of their investigation concerns safeguarding risk as part of the transition to the National Disability Insurance Scheme (NDIS). Carers Victoria understands a discussion paper regarding safeguarding risk within the NDIS will be released during 2015 by the National Disability Insurance Agency (NDIA).

Of note to the Ombudsman's investigation are findings from recent research in the UK⁹ that raised the potential of greater risk of abuse and neglect, including financial abuse,

⁹ National Institute for Health Research School of Social Care Research (2014) Risk, Safeguarding and Personal Budgets: Exploring relationships and identifying good practice. Accessed at <http://www.kcl.ac.uk/sspp/policy-institute/scwru/res/knowledge/risks.aspx>

following the move to personal budgets or direct payments. Particular concerns are where unregulated care workers are used, and where relatives and others are managing the money. On the other hand, personal budgets may also enhance personal safety through increased control by the person over their own care. The UK study found no strong evidence of higher rates of financial abuse for those with personal budgets, but notes the requirement for better data in this area. The study concluded that monitoring and review of personal budgets are important ways to identify the potential risks of abuse.

Carers Victoria recommends careful consideration be given to the balance of safeguarding risk with increased choice and control as Australia moves towards consumer directed models of disability service delivery.

8. Conclusion

In conclusion, Carers Victoria appreciates the opportunity to present information on the experience and impact for carers who have suspected, witnessed or becoming aware of abuse against the people they care for while receiving disability sector services, including how this abuse is reported and investigated. Carers Victoria staff are available to discuss the information provided in this submission with the Victorian Ombudsman or staff as part of their investigation.