

**Submission
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INQUIRY INTO INQUIRY INTO ELDER ABUSE IN NEW SOUTH WALES

Organisation: Mental Health Carers ARAFMI NSW Inc.

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Submission from
Mental Health Carers ARAFMI NSW Inc.,
to the
NSW Legislative Council's Enquiry into
Elder Abuse
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Introduction

Background

This submission is to the NSW Parliamentary Enquiry into Elder Abuse in NSW from Mental Health Carers ARAFMI NSW.

The enquiry

The General Purpose Standing Committee No. 2 of the NSW Legislative Council has called for submissions in relation to its enquiry into matters relating to elder abuse in New South Wales. The Committee is interested in hearing from interested parties in relation to the following:

1. The prevalence of abuse
2. The most common forms of abuse and the most common relationships or settings in which abuse occurs
3. The types of government and/or community support services sought by, or on behalf of, victims of elder abuse and the nature of service received from those agencies and organisations
4. The adequacy of the powers of the NSW Police Force
5. Identifying any constraints to elder abuse being reported and best practice strategies to address such constraints
6. Identifying any strength based initiatives which empower older persons to better protect themselves from risks of abuse as they age
7. The effectiveness of NSW laws, policies, services and strategies, in safeguarding older persons from abuse
8. The possible development of long-term systems and proactive measures
9. The consideration of new proposals or initiatives

About ARAFMI

Mental Health Carers ARAFMI (formally known as the Association of the Relatives and Friends of the Mentally Ill), is a Non-Government, member based community organization providing advocacy and a range of services responsible for supporting friends and family of people living with experience of a mental illness.



ARAFMI was formed in 1975 by Margaret Luke's and a group of carers who recognized a need for a service to address the issues that caring for someone with a mental illness presents. Their vision is as follows, "Our vision is for a community that understands and responds to the impact of mental illness on families and carers and the many people who are living with a mental illness."

ARAFMI is a Peak organization or advocacy group associated with other industries or groups of allied interests. They represent Mental Health Carers views and needs at the state-wide level to the NSW Ministry of Health. Their purpose is to develop standards and procedures when lobbying governments or promoting the interests of their members. ARAFMI is the peak body in NSW for carers. There are six main offices throughout Australia. The NSW office in Woolloomooloo provides state level advocacy to the NSW Health Department regarding carer issues. It is also the base for ARAFMI NSW board and its consultations.

ARAFMI operates a Carer Connection Helpline that provides support, information and referrals to local services. They connect families and carers of people living with a mental illness to support services, information and education. They provide advice about local mental health services to callers from across the state. Specific issues and experiences may be recorded for advocacy purposes. ARAFMI supports diverse groups of carers including those in rural NSW, those of Aboriginal or Torres Strait islander descent, and carers from culturally and linguistically diverse (CALD) backgrounds. They also assist young carers, especially siblings and children of individuals living with a mental illness. Arafmi facilitates many groups, workshops and training events. These include Mental Health First Aid, Borderline Personality Disorder Workshops, and the Mental Health Carer Support Workers Forum.

The organizational structure consists of the Board, CEO, staff, students and volunteers. A voluntary Board of Management in NSW deals with the issues raised and are voted in biannually by members of the organization. Within the Board at least 51% must be carers of someone with a Mental Illness. This is in order for the organisation to remain connected to the needs of families and friends with a mental illness. ARAFMI also convenes a Mental Health Carer Peak Advisory Committee (C-PAC) and sub-committees dealing with Young Carer, Older Carer and Alcohol and Drug Carer Issues; and circulates weekly email updates to its networks of carers and carer support workers.

Partners with ARAFMI are the NSW Consumer Advisory Group, Mental Health Co coordinating Council (MHCC), Australian Government: Department of Health and Ageing, Mental Health Association of NSW and Mental Health and Drug and Alcohol Office (NSW Health). ARAFMI is currently funded by the Mental Health Commission. ARAFMI also receives membership money, donations and charity with specific project funding from various sources.





The Prevalence of Abuse

Current situation

ARAFMI believes that the incidence and prevalence of elder abuse in NSW is more common than we, as a society, care to acknowledge. While we provide a help line for people experiencing the challenges associated with mental illness including dementia, like other organisations it is difficult for us to estimate the prevalence of abuse as the callers do not necessarily recognise the situation as abuse. We believe that many cases go unreported and the details of those incidences that are reported are not collected and analysed in a consistent and comprehensive manner.

In addition, Elder abuse can be very difficult to identify, as many abusers and victims of abuse do not recognize it as such. What may be abuse in the experience of the older person, or in the assessment of an experienced observer, can be defined by others as the carer just “doing what is best for the older person”. In some cases carers lack insight to know their behaviour is abusive.

Of particular concern to ARAFMI are situations where the older person may have filled the role of carer, particularly to an adult child with experience of mental ill health. Many parents are reluctant to forsake such a role when there is no obvious alternative supported accommodation available for their loved one; however as they age they become less capable of supporting them. At the same time, their loved one may lack insight into the relationship and behave inappropriately towards their long time carer, particularly if medication compliance is an issue. In such cases it is the system which does not provide adequate support to people living with psycho-social disability which is as much the abuser as the adult child. In such cases the provision of alternative accommodation options would both reduce the chances of abuse as well as greatly reducing the older person’s anxiety about what will become of their child once they pass away, which is often an unwelcome preoccupation for such people.

The Sydney Morning Herald (16/10/2015) recently reported that research completed by Monash University found that up to 5 per cent of Australians over 65 have experienced financial abuse. It also found women over 80 were most at risk and their children were most likely to be the perpetrators. In addition, the World Health Organisation estimates 1 in 10 older people around the world experience some form of elder abuse each month; but this is likely to be a low figure, as, they estimate, only one in 24 cases of elder abuse is reported.



What needs to happen

What is needed is a compulsory system of reporting of elder abuse and a consistent framework for the collection and analysis of data on the incidence and prevalence of elder abuse from all relevant NSW government and non-government agencies. Such a reporting system could have similarities with the current system of reports of child abuse. In situations where this is caused by older people persisting in a caring role for which they are no longer equipped, they should be given top priority for alternatives to be found for the person they care for, recognising that they will usually have behaved inappropriately through no fault of their own; or with reduced responsibility due to impaired insight. For professional carer's of older people however, sanctions are appropriate for reported abuse.

In NSW where a person in an occupational group covered by the Legislation 'suspects on reasonable grounds that a child is at risk of significant harm' then they are required to report. A child or young person "is at risk of significant harm if current concerns exist for the safety, welfare or wellbeing of the child or young person because of the presence, to a significant extent, of ... basic physical or psychological needs are not being met ... physical or sexual abuse or ill-treatment ... serious psychological harm".

We believe that the NSW Parliament should give careful consideration to the introduction of legislation requiring any person, in an appropriate range of occupations and roles, be required to report when they have reason to suspect that an older person is being abused or at risk of being abused.

The definitions of abuse should be sufficient to cover the recognised areas of abuse and not limit the definition of abuse to types of abuse that may not currently be identified. The age limit for the victim needs to be broad to cover incidences where people younger than retirement age are limited in their capacity to resist the attempts of abuse due of mental illness, disability and cognitive impairment or frailness due to age.

The range of occupational groups and roles required to report would need to be broad and appropriate to cover these likely to be engaging with the victim or potential victim and, in addition to those in traditional caring roles, should include officers of financial institution, solicitors, local council officers, officer of Commonwealth agencies, for example Centrelink, Veterans Affairs, etc.



Most common forms of elder abuse.

From our experience at ARAFMI, the most common types of elder abuse are financial abuse and emotional abuse. In addition, elders can be exposed to sexual and physical abuse, and abuse by neglect, omission and obstructive bureaucracy by government agencies.

Financial Abuse

Financial abuse may be easier to identify than some other forms of abuse because the outcomes may be more apparent. However, all kinds of abuse have an emotional effect on an older person and it is the emotional aspects of abuse that are virtually impossible to measure and very difficult to detect. ARAFMI supports the recommendations of the recent paper from Alzheimer's Australia on preventing financial abuse of people with dementia.

These recommendations include:

- The introduction, by the NSW Government, of a Public Advocate whose role would include the investigation of reports of financial abuse
- The examination, by the NSW Law Reform Commission,
 - of the establishment of a register for Enduring Powers of Attorney
 - the most appropriate mechanisms to respond to financial abuse of people with dementia
 - of the adequacy of current law covering financial abuse in the Powers of Attorney Act 2003
- The establishment by the NSW Police Force of Vulnerable Communities Officer positions in each Local Area Command
- An education program sponsored by the NSW Government
 - to ensure that people who are appointed as attorneys under Enduring Power of Attorneys understand their responsibilities
 - to the general public and targeting aboriginal and CALD groups, about financial abuse and planning ahead tools
- the introduction by the Commonwealth Government of reforms to the Australian Prudential and Regulatory Authority to require banking and financial services institutions to develop internal systems and processes to prevent financial abuse and establish protocols to report suspected financial abuse of customers to state Public Advocates
- that banking and financial services institutions



- provide mandatory training to their staff on identifying financial abuse and about dementia using the 'Is it Dementia?' training resource developed by Alzheimer's Australia

Case study one - financial abuse

Cathleen was diagnosed with Parkinson's disease around age 72. Cathleen's primary carer was her daughter Clair. However, after consulting with her solicitor she gave Clive and Carol, her other two children, power of attorney over her financial affairs and property. Subsequently, the relevant financial institutions were informed who was legally able to access Cathleen's accounts.

Clair took Cathleen to the bank to close her accounts, withdraw several thousands of dollars in cash and ensure Cathleen's pension was being deposited into her own account. Despite the power of attorney, Carol was refused by the bank to receive information when Cathleen's card was taken by an ATM after it had been cancelled by Clair. Carol and Clive were correct in their assumption that they no longer had access to their mothers account.

The bank staff were oblivious to any wrong doing on their behalf and denied their failure to adhere to the law regarding the relevant power of attorney documents. This is seen to have been a significant contributing factor to financial abuse suffered by Cathleen.

- provide information to their customers about how to protect themselves from financial abuse and steps they can take to plan ahead
- that the NSW Law Society provides training
 - about financial abuse to lawyers and includes this as part of continuing legal education requirements
 - about dementia to lawyers using the 'Is it Dementia?' training resource developed by Alzheimer's Australia
- All funded aged care organisations in NSW be required to make staff aware of their responsibilities and obligations under the NSW Interagency Protocol for Responding to Abuse of Older People.

Abuse of older persons by neglect from government agencies and bureaucratic indifference

Of major concern to ARAFMI are those older persons who are at risk or suffering from abuse from adult children living with a mental illness. In many circumstances the parent has been the carer of their child with mental illness over a long period. As they are now ageing the burden of caring from an adult with



severe mental illness may be one they no longer have the strength to bear. Inadequacies of service provision in relation to adult mental health services, Specialist Mental Health Services for Older Persons, public housing and respite service all take their toll on older carers.

Ageing parents of adults with a mental illness face the risk of emotional, physical and financial abuse either directly from the behaviour of their child caused by a deterioration of their mental illness or resulting of a failure of treatment. The failure of treatment may arise from the adult living with a mental illness, deciding not to continue with medication or other treatment or the failure of the treating service to provide adequate follow-up and support. Mental health service providers tend to focus on the needs of the identified patient (in this case the child) and neglect the needs of the carer (the ageing parent).

Programs providing respite for carers are a Commonwealth Government responsibility and these programs have been recently combined with the former Home and Community Care Program to form the Commonwealth Home Support Program. In addition, the NSW Government recently transferred responsibility for Home Care in NSW, with some respite services, to a non-government agency. These reforms reduce the capacity of the NSW services sector to provide or secure respite services to ageing carers of persons with a mental illness.

Information provided to ARAFMI is that the level and availability of respite services to this client group substantially fail to meet the demand. Fragmentation of service delivery, for example, between state-based mental health services and commonwealth funded respite services, results in a failure of the system to meet the needs of this vulnerable group in the community, and may in the view of some, constitute a form of abuse.

Continuing reforms to the aged care system by the Commonwealth Government to encourage people to age at home have seen the increase in the number of aged people cared for at home, often with a live in carer. While these initiatives are supported it is important to also have regard of the impact caring for an older person at home can have on the carer. The recent introduction of Consumer Directed Care Packages supports respectful person-centred care. However, there is a danger that where there are deficits in service provision the burden of care remains with the carer, many of whom are also ageing. There is a recognised inadequacy in the package of care provided for carers to support them in their role and prevent or minimise carer burnout which may lead to abuse.

What is needed

Increased access to respite services are needed for older persons caring for an adult with mental illness; as well as increased availability of supported accommodation for people living with experience of mental



illness. If accommodation with the older person is no longer appropriate, then such people need to be prioritised for alternatives as the older carer is unlikely to accept any option that does not see their loved one appropriately housed. Community aged care and housing services need to work closely with state based mental health services to ensure that they are aware of the needs of this client group.

Services sought by victims of abuse

In many of the case studies ARAFMI is aware of, victims of abuse did not seek services for a variety of reasons. Some people had no idea about how to go about reporting elder abuse, some used the elder abuse line and social work services. At ARAFMI, we are aware that most services that take calls from victims of abuse keep only qualitative data which does not lend itself to quantitative analysis although most of these are seeking services and are referred on.

What is needed

The development of a single data collection system for recording incidents of risk, suspected or actual elder abuse, as recommended above, will assist the NSW community to assess the range of services and volume that victims of abuse need.

The adequacy of NSW police to respond.

Of the cases of elder abuse with which ARAFMI is aware no police involvement was sought. This may be because the abuser is often a close friend or relative and the victim determines that it is a social or personal matter and not a criminal matter. When carers, who were involved in our case studies, were asked about how they felt in regards to police involvement the response was generally one of surprise as to why police would be asked to be involved in such a personal matter. It simply did not occur to them to contact police. When an older person is abused, there is often a love or a sense of responsibility for the abuser particularly when it involves one of their children. Carers also perceived an inability of police to be able to handle sensitive cases related to elder abuse gently and respectfully.

What needs to happen

ARAFMI supports the recommendation of Alzheimer's Australia of the appointment of Vulnerable Communities Officers in each local area command. The role of these officers would be to support vulnerable people including, people with mental illness, disabilities, and older people, including those with dementia at risk of or who have suffered abuse or neglect. The officers will need to be provided with specific training in aspects of financial, sexual and emotional abuse, dementia and mental illness. Their



role would be both preventive and investigative and they could provide a source of reference for other occupational groups in the community, such as financial institution officer, community service providers and social groups, around which older people can be protected and rescued from abuse.

Identifying constraints to elder abuse being reported and best practice strategies to address such constraints.

The biggest contributor to elder abuse being under-reported is the fact that the abuser is often a close family member or friend, very often a child of the victim. The victim may have had a responsibility or duty of care to that person in the past. There are many different reasons for constraints on reporting and the reluctance of victims to report.

Isolation: Social isolation may play a major part in elder abuse under-reporting. The abused older person is often reliant on the abuser, not only for their care needs but also for their socialization. In these situations, the primary carer is usually able to control who the older person sees or doesn't see. This level of isolation also includes older persons in residential aged care and receiving aged care at home.

Dominant personalities: In the community, amongst family groups, the abuser may frequently be the person that historically has had emotional dominance within the family unit. This can result in other family members feeling severely compromised when they attempt to report abuse. There is a fear of repercussions for whoever reports the elder abuse, whether the reporter be the older person themselves or a person who witnessed the abuse. Some people expressed a fear of the abuser and that the abuse will increase as a result of a report.

Aggression/abuse is seen as normal: Because elder abuse is most likely to occur amongst family, and if this type of behavior has been common place in a particular family or group, it is often not recognized as abuse, but just part of normal behavior. As people age their ability to respond to or deal with what has been common is diminished and there is a shift in power. For example, a parent may have been quite capable of dealing with an aggressive child, but as the child grows and the older person becomes more vulnerable both physically and mentally the child becomes the stronger character in the relationship.

Family secrets: There can also be sense of shame at the behavior of a certain family member or carer who is abusive and there is a reluctance to seek outside assistance; "This is a family matter to be dealt with within the family unit."



Reluctance to ask for help: During the later years of life several components contribute to a sense of loss and inadequacy, and these combined with some diminished capabilities may increase the reluctance to ask for help. Asking for help does not come easy to many people, and may be particularly apparent in older generations who came to majority prior to the introduction of many of the social services younger generations take for granted today. Admitting to not being able to protect oneself against abuse can be very difficult for an older person to accept.

Empathy for the plight of the abuser: In some instances of abuse it has been put down to carer burn out. What is needed is more carer support.

Older people lose their voice: As people age and their responses are slower there is a tendency for the community at large to almost disregard the need of the individual and there is often a focus on the needs of what the carer wants for the older person.

What is needed

What emerges from this discussion on the constraints on the reporting of elder abuse is the need for a response that is non-judgemental, gentle and emphatic. Also to improve services for older persons suffering, abuse officials and services need to be aware of the signs that abuse is occurring even when it is not specifically reported. Awareness training of all front line workers on the potential for abuse and the signs and signals that indicate abuse is needed. In addition, responses by service providers need to be appropriate to the complex range of issues associated with dependent relationships within families.

Identify any strength based initiatives which empower older persons to better protect themselves from risk of abuse as they age.

Enduring guardianship, advanced care plans and enduring power of attorney
There is a level of confusion in the community over the respective roles of these three types of documents, their use and how they can be established and used.

Enduring guardianship

The Guardianship Act 1987 (NSW) was amended in 1997 to make it possible for any adult to appoint an enduring guardian. This person then becomes a substitute decision-maker for older persons in relation to their choice to make lifestyle and health care decisions should they lose the capacity to make your own



decisions at some time in the future. The enduring guardianship takes the form of a formal signed document witnessed by an appropriate person.

While the appointment of one person as an enduring guardian is common practice, the appointment of two or more people as enduring guardians may have some advantages to prevent future abuse. Two or more enduring guardians can be given different functions, for example, one to make lifestyle decision and one health related decision; or they can be required to act together. To limit the potential for abuse it is recommended that a number of people related to or associated with the older person be aware of the existence of the enduring guardianship document, even if they are not the appointed guardian. In this way abuse by the appointed guardian may be given a greater chance of detection.

An enduring guardianship arrangement can include an 'access function' which give the enduring guardian authority to decide:

- who can have contact with the older person (including written or telephone contact);
- when visits or contact should occur, for how long, and in what circumstances.

This function may be particularly important to reduce the risk of abuse by some family members or close

Case study number two – advanced care plans

Arthur is a 95 year old man, living with a diagnosis of Dementia. When his wife passed away, his son Andrew was made power of attorney. Arthur's house was soon sold, exacerbating his cognitive decline which resulted in him being placed in an aged care facility. Alison, his other child, travelled from interstate at this news to debate with professionals to ensure his sedating medications were cancelled and he was taken out of the facility to familiar places. The lack of an advanced care plan in this situation is seen to be a significant contributor to his distressing experience. The application of an advanced care plan would have allowed Arthur to communicate his daily living desires and lifestyle choices.

friends. Alternatively it may provide the guardian with the power to limit access by those who may detect abuse. Should there be genuine concern for the older person's welfare because of the action or inaction of the appointed enduring guardian, the person with the concern can request the Guardianship Tribunal to review the appointment of the enduring guardian. In reviewing the appointment of an enduring guardian, the Guardianship Tribunal may revoke or confirm the appointment, or vary the functions of the appointed enduring guardian.



Advanced Care Plans

Advanced care plans (also called advanced directives) are entered into by a person concerned that their wishes in relation to future treatment need to be known to those concerned, particularly their health care providers. It involves the older person, their family and, possibly their health professionals, talking together about the type of health care the older person would want to receive if they were seriously ill or injured and unable to say what you wanted. Ideally these conversations are not left to the later stages of an older person's illness.

Currently, in NSW, there is no single form or document a person must use to write down their advanced care plan wishes and there is no central register of people who have signed an advanced care plan. Guidelines on advanced care planning for older persons with a mental illness guidelines have also been developed. Unlike enduring guardianship arrangement advanced care plans, or advanced directives, may not be legally binding.

Enduring Power of Attorney

A power of attorney is a legal document that appoints a person to act on behalf of the older person in relation to the older person's property and financial affairs. This person, for example, may be appointed with authority to buy and sell property and operate the older person's bank accounts.

An ordinary power of attorney generally commences at the time it is signed and the attorney can start acting straight away. It ceases to have any effect, and therefore cannot be used, after the older person loses capacity. An enduring power of attorney also commences at the time it is signed. This means that the attorney can start using the power of attorney immediately before the older person suffers any loss of capacity. An enduring power of attorney continues to have effect after the older person loses capacity. The granting of an enduring power of attorney to a person likely to be dishonest, unethical or unscrupulous is of major concern in relation to elder financial abuse.

What is needed

ARAFMI supports the recommendation for a mandatory state-wide register of enduring powers of attorney to enable authorised persons and particularly officers of financial institutions to satisfy themselves of the legal capacity of individuals to make decisions in relation to older persons or where they are of the view that the older person may be a risk of financial abuse.



Consideration should also be given to the establishment of a state-wide non-mandatory register for enduring guardianships and advanced care plans (advanced directives). Such a register would enable front line health care staff, who may not be the older person's usual health professional, accessing their wishes in relation to health care decisions.

There is also a need for a state-wide government sponsored education campaign in relation to enduring guardianship arrangements, advanced care plans and enduring power of attorney arrangements.

Effects of NSW law, policies, services and strategies.

Recording of next of kin and carer

In addition to the comments above in relation to establishment of a register of enduring powers of attorney consideration should be given to changes in policy with in NSW Public health agencies around the collection of data on alternative decision makers and next of kin. This review of policy and practice should take into consideration a number of issues around current practice concerning the risk of elder abuse from family members.

It is common practice for health and aged care providers, for example, to record only one next of kin or person for contact. Issues arise where the next of kin may not be the older person usual carer, for example, where a husband or wife is still alive but a child has taken over the role of care for an older person. Service providers should at least be open to taking enquiries from more than one next of kin and/or carer.

Challenges also arise where there is more than one person claiming to be the carer or next of kin, say in families with more than one child of the older person. Although it may be time-consuming and inconvenient service providers should adopt policies and practices that give recognition to the wishes and views of more than one carer or family. This may be an important safeguard in the area of preventing or detecting abuse.

Communicating with older people

As a person ages, even when their capacity is intact, their response times may start to slow giving the impression of a lack of capacity in the older person. Some professionals and service providers can fall into the habit of talking about older people in the third person, even when that person is in front of them. They may also regard the opinions and wishes of the older person as less important or inferior than that of the carer or next of kin. That is, the carer is given more credibility and influence in decision making than the individual themselves and this is often for no other reason except the individual is elderly. In the area of elder abuse this practice may have the double effect of failing to hear the concerns over abuse by



the older person and give credence to the wishes of the person inflicting the abuse. While we need to be mindful of issues of confidentiality and sharing of personal information, service providers do not need to breach these laws if they are to merely listen to other carers and consider their opinions, when there is concerns of elder abuse.

We should also be mindful that not all families have a husband wife and some kids. Diversity should be considered in the development of legislation, and reviews of policy and practice. This should include but not be limited to same sex couples and chosen families. Same sex attracted individuals may be more vulnerable to abuse from their partners where they experience the added isolation from society. Alternatively, the rights of same sex spouses need to be taken into consideration where an older person also has siblings who claim next of kin status.

What needs to happen

Consideration be given to the development of a mandatory central state-wide register of powers of attorney, a non-mandatory central register of enduring guardianship and advance care plan agreements. This will need to be supported by continuing educational and information campaigns about the confidentiality and safeguards around such registers and who has access to them. A broad community wide information campaign to raise awareness of the importance of these mechanisms to protect the interests of older people and to prevent abuse.

A review of policy and practice in relation to recording of carer and next of kin status in relation same sex couples and chosen families be undertaken by government agencies.

The possible development of long-term systems and proactive measures

People from non-English speaking backgrounds

The ageing of post-war immigrants presents emerging challenges in relation to the risk of elder abuse and detection of continuing abuse and many older Australians of non-English backgrounds will lose some of their English skills. Added to the cultural norms of many immigrant communities where older persons become the responsibility of their children. However, their Australian raised children may not share the expectations of their parents in relation of their fidelity and responsibilities towards their parents.

Community education may have an important role in stimulating discussion on the roles of older persons and their children among non-English speaking communities.



Need for reporting systems acceptable to older persons

What is necessary is to provide older people with avenues of reporting that are non-judgmental, perhaps in some cases forgiving. This mechanism for reporting also need to ensure that the older person can feel safe and retain their sense of dignity. This is important as victims of abuse often feel shame and embarrassment that this has occurred to them, especially when the abuser is a loved one. We recommend that consideration be given to the development of a single state-wide reporting system on suspected and perceived elder abuse similar to the current system in place in relation to child abuse.



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