Final grant report: Protecting People with Dementia from Financial Abuse

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<tr>
<th>Project title</th>
<th>Protecting People with Dementia from Financial Abuse</th>
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<td>Grant recipient</td>
<td>Alzheimer’s Australia NSW</td>
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<td>Position</td>
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<td>Law and Justice Foundation awarded amount</td>
<td>$22,150.00</td>
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<td>Grant period</td>
<td>July 2013 – August 2014</td>
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**Description of the project**

>*Describe the project in just enough detail so that anyone can understand it. What was the aim of the project, who was the intended audience and what strategies did you implement to achieve the aim?*

This Alzheimer’s Australia NSW (AlzNSW) project aimed to:

1. Understand how financial abuse of people with dementia occurs and identify gaps in law and policy that enable it to occur;
2. Identify what will reduce the likelihood of financial abuse and influence law and policy makers to initiate required changes;
3. Educate service providers and people with dementia and carers about how to safeguard themselves and prevent financial abuse.

The intended audience included policy makers, human service providers, professionals in the legal and financial sectors, and people with dementia and carers.

The key strategies implemented to achieve the project aims were:
- Research project
- AlzNSW discussion paper
- Education session for AlzNSW services staff about financial abuse
- Alzheimer’s Australia help sheet for consumers

**The project – what happened?**

*How did the project come about?*

AlzNSW is the peak body for people living with dementia and strives for a society that is committed to the prevention of dementia and that values and supports people living with dementia. Our mission is to minimise the incidence and impact of dementia through leadership, innovation and partnerships - in advocacy, policy, education, services and research.
There are more than 321,000 Australians living with dementia. Without a major medical breakthrough, this is figure is expected to increase to almost 900,000 by 2050 (AIHW, 2012). Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person’s functioning. Symptoms include loss of memory, intellect, rationality, social skills, motor skills and physical functioning. The loss of these cognitive abilities increases the vulnerability of people with dementia and increases their risk of being financially abused.

AlzNSW is aware that people with dementia are being financially abused yet many cases go unreported. The number of unreported cases is likely to be high due to feelings stigma, shame and embarrassment experienced by people who are financially abused. Furthermore, the impact of financial abuse may be considerable because people with dementia may have diminished capacity to recall it, or lack insight to understand the instance/s of abuse. Even in cases where they do detect and report abuse they might be dismissed as being an unreliable witness or confused and lacking credibility.

Alzheimer’s Australia NSW consumers raised this as an issue of concern which they wanted us to address. As a consumer-based advocacy organisation we are committed to listening to those we serve and acting on their behalf. AlzNSW has eight Consumer Advisory Groups who advise us of topics for research and policy development. The topics are therefore ones that are important to them and suggest that gaps exist in policy and practices which diminish the quality of life of people with dementia and their carers.

Our colleagues at the Alzheimer’s Society in the UK published a research report in 2011 about financial abuse of people with dementia. However a review of Australian and international literature revealed that limited research had been conducted about financial abuse of people with dementia. Similarly, there are very few education and training resources targeted at people with dementia and their carers and/or service providers about how to prevent and protect people with dementia from becoming victims of financial abuse.

Briefly set out the project stages and what happened in each stage.
AlzNSW proposed the following strategy to achieve the project aims:

1. Ascertain perceptions and understandings of financial abuse.
2. Describe instances of financial abuse experienced by people with dementia within NSW.
3. Understand current approaches to identification, reporting and conviction of financial abuse cases.
4. Identify gaps and develop solutions/recommendations to reduce the impact and incidence of financial abuse of people with dementia.
5. Influence law and policy makers to understand the gaps and make changes that the research identifies could reduce the impact and incidence of financial abuse of people with dementia.
6. Train key contacts for people with dementia about how to: recognise people at risk and people being abused, stop financial abuse of people with dementia from occurring, and incorporate knowledge from the research into their respective Programs they deliver.
7. Provide information to people with dementia and their families about practical steps they can take to minimise the risk of abuse occurring, and if it does, how to reduce the impact and seek justice.

These steps were designed to inform us about what needed to change, how to change it and who the key stakeholders are. Our strategy then evolved to focus on educating key stakeholders (politicians,
bureaucrats, people with dementia, their families, key contacts for people with dementia) and advocating for change to the relevant policies and laws.

The research component of this project was a mixed-method design, developed to collect data and information from a range of sources and stakeholders including people with dementia, carers, and professionals from a range of sectors. The project received approval from the Macquarie University Human Research Ethics Committee (HREC) as per AlzNSW research protocols.

A project advisory group was established. The group members were:

- Ms Louise Biti (Aged Care Steps)
- Ms Lee Critchley (Legal Aid)
- Mr Andrew Gale (Chase Corporate Advisory)
- Ms Kerry Marshall (NSW Elder Abuse Helpline and Resource Unit)
- Mr Nicholas O’Neill (AlzNSW Director and former President of the NSW Guardianship Tribunal)
- Associate Professor Carmelle Peisah (Specialist Mental Health Services for Older People, Northern Sydney Local Health District and Capacity Australia)
- Mr Russell Westacott & Ms Melissa Chaperlin (The Aged Care Rights Service - TARS)

Focus groups were conducted in October 2013 with members of the eight Alzheimer’s Australia NSW Consumer Advisory Groups throughout NSW. At the time these groups met in Sydney, Wollongong, Orange, Wagga Wagga, Port Macquarie, Newcastle, Cooma and Armidale. The purpose of the focus groups was to gain insights into community understandings and perceptions of financial abuse. Focus groups went for approximately one hour and were audio recorded with the informed consent of the participants. Data was analysed thematically to identify common views and perceptions.

In-depth semi-structured interviews were conducted with four family members of people with dementia who had been financially abused. Each interview was audio-recorded with the informed consent of participants and participants received a $50 gift voucher to thank them for their time and for sharing their story.

Professionals in the legal and financial sectors and staff of community service providers throughout NSW were invited to complete an online survey about their experiences of supporting people with dementia who have been financially abused and about their suggestions for reducing the incidence and impact of financial abuse. The survey was available online from November 2013 to February 2014 and 89 responses were received.

We also consulted a number of key stakeholders including the Office of the Public Guardian (OPG), the Guardianship Division of the NSW Civil and Administrative Tribunal (NCAT) and NSW Police. Legal, policy and practice gaps were identified through the research and the collective knowledge of the project advisory group. A meeting was held in April 2014 to workshop ideas for policy and practice reforms. Recommendations were developed in consultation with the advisory group to ensure that they were feasible and sustainable.

The first output for this project was an AlzNSW discussion paper about financial abuse of people with dementia, Preventing Financial Abuse of People with Dementia (available online at http://www.fightdementia.org.au/new-south-wales/research-nsw.aspx). This discussion paper was launched at NSW Parliament House on June 18, 2014. It reports the findings of our research project and provides a number of important recommendations.
The discussion paper was sent to relevant NSW and Australian Government ministers, advisors and policy makers. The paper is available on the Alzheimer’s Australia NSW website. We are also seeking to publish the findings in journal articles and sector newsletters, and to present at conferences and community forums. To date, we have presented to the members of the Guardianship Division of NCAT and staff at the Financial Ombudsman Service. Short articles were published in the Queensland Elder Abuse Prevention Unit (EAPU) June newsletter and the July/August edition of the Australian Journal of Dementia Care (AJDC). A longer article will be published in the AJDC in late 2014 or early 2015, and we are submitting an abstract for the Alzheimer’s Disease International (ADI) conference to be held in Perth in April 2015. We will continue to identify appropriate avenues to disseminate the research findings and recommendations. A Final Report has been provided to the Macquarie University HREC.

The second output is a professional development session for AlzNSW services staff. This session will be delivered in conjunction with a member of our expert advisory group for the project, Associate Professor Carmelle Peisah, in late 2014. The session will focus on how to: recognise people at risk and people being abused, stop financial abuse of people with dementia from occurring, and incorporate knowledge from the research into their respective programs they deliver.

The third output is a new Help Sheet for people with dementia, their carer and service providers who support them. Alzheimer’s Australia Help Sheets are a national resource and their development is coordinated by the Alzheimer’s Australia Victoria office. The Help sheet is using data gained from the research to provide information to people with dementia and their families about practical steps they can take to minimise the risk of abuse occurring, and if it does, how to reduce the impact and seek justice. We are currently developing the content for the Help Sheet. Once the content has been finalised we will pass it on to our colleagues in Victoria. At this stage we are unsure of the timeline for approval and publication of the Help Sheet; we will update the Law and Justice Foundation on its progress in due course.

The practical implementation of the project findings and resource materials will be achieved through ongoing activities not funded by this grant. AlzNSW will undertake education and advocacy activities to increase awareness and reporting of abuse, whilst improving safeguards and protections for people with dementia. We will advocate for legal changes to be made if necessary to protect people with dementia from financial abuse as part of its ongoing systemic advocacy role for people with dementia.

If grant materials were produced:

**How were they distributed?**

All attendees at the Parliamentary Friends of Dementia event on June 18 received a copy of the discussion paper. Following the launch, copies of the paper were sent to the research interview participants, project advisory group members, AlzNSW consumer advisory group members, relevant MPs and Government departments. The paper is publicly available on the AlzNSW website.

**What was the extent of the distribution?**

As the report is available on the website, we cannot state the extent of the distribution as it is unknown how many people have viewed the PDF copy online.

Also, other organisations are also promoting the discussion paper. For example, a link to the paper has been placed on the EAPU Qld website.
Organisations from outside of NSW in Victoria and Queensland have contacted AlzNSW, indicating that the report has had extensive distribution and national relevance.

**Now that the project has concluded, how did the implementation and/or the outcome differ from what was originally intended? Did anything surprise you? Were there any unintended outcomes?**

We anticipated difficulties in recruiting interview participants as this is a sensitive topic to talk about, however, recruitment was challenging and took longer than originally planned.

We expected quite a bit of media interest in this topic. Previous launches of AlzNSW discussion papers have generated significant media coverage of issues. Unfortunately, the launch of this paper coincided with the release of the NSW State Budget and consequently we did not get as much mainstream media coverage as we would have liked. However we did receive an excellent response to the paper and the issue on the AlzNSW social media sites (Facebook, Twitter and Dementia Daily). See for example, [http://www.dementiadaily.org.au/greater-protections-needed-to-prevent-financial-abuse-of-people-with-dementia/](http://www.dementiadaily.org.au/greater-protections-needed-to-prevent-financial-abuse-of-people-with-dementia/)

Despite the low media coverage, the feedback and direct engagement we have received since the launch of the discussion paper has been extremely positive. It has highlighted the need for this work to shine a light on the issue and identify possible solutions and strategies to address the financial abuse of people with dementia.

There are many interested stakeholders who have contacted us since the launch, keen to discuss how they can assist and what more can be done. To facilitate this, AlzNSW organised a meeting on August 11 to discuss what activities are currently happening and what needs to be done. In attendance at this meeting were representatives from the OPG, NSW Trustee and Guardian (TAG), Guardianship Division of NCAT, Elder Abuse Helpline, Council on the Ageing (COTA), Ministerial Advisory Council on Ageing (MACA), NSW Family and Community Services (FACS), Office of the Legal Services Commissioner, NSW Law Society, as well as experts in the legal and financial sectors. This meeting has resulted in the establishment of a Financial Abuse Interagency who will continue to meet regularly and collaborate on initiatives to prevent financial abuse of vulnerable older people and specifically people with dementia.
Evaluation

**What questions did you ask to evaluate whether you had achieved your aim?**

Does the paper articulate how financial abuse of people with dementia occurs?
Does the paper identify gaps in law and policy?
Does the paper identify actions that could reduce the likelihood of financial abuse occurring?
Does the paper make recommendations for law and policy makers which are support by the research evidence?

**Yet to be asked**

How many attend the AlzNSW staff training session?
Is a Help Sheet produced?
How many downloads of the Help Sheet in one month from release?
Is the content of the training and Help Sheet useful?
Is the content support by the research evidence?

**What data did you gather to answer your questions?**

Research data
Discussion paper
Advisory group meeting minutes
Feedback from general public, Government policy makers, and service providers (meetings, emails, phone calls)
Media metrics following launch of discussion paper

**Yet to be collected**

Training registrations
Weblink to Help Sheet
Pre- and post-training surveys

**Did you achieve your aim? What did you find out?**

We are in the process of achieving the aims of the project.

**Aim 1: Understand how financial abuse of people with dementia occurs and identify gaps in law and policy that enable it to occur.**

The discussion paper identifies the main ways in which financial abuse of people with dementia occurs. Most people are financially abused by a family member, most often children. More than sixty-five percent of respondents to our survey indicated that children are most often identified as the perpetrators of abuse, and over ninety percent of respondents indicated someone known to the victim is most often the perpetrator. Much financial abuse is perpetrated through the misuse of an Enduring Power of Attorney (EPOA). Not all financial abuse of people with dementia is perpetrated by family members and those holding an EPOA though. People with dementia, particularly those who live alone, are susceptible to exploitation and abuse by neighbours and friends who prey on their vulnerability.

There are many gaps in law, policy and practice that enable financial abuse to occur including no registration of EPOA, and, subsequently, no monitoring or accountability processes; lack of understanding of responsibilities of EPOA; lack of criminal offences outlined in the Powers of Attorney
Act; failure of some solicitors to properly assess the capacity of people with dementia appointing a new EPOA; lack of understanding about how and who to report suspected financial abuse to; barriers to investigation of cases of financial abuse; and limited means for resolution.

**Aim 2: Identify what will reduce the likelihood of financial abuse and influence law and policy makers to initiate required changes.**

A number of possible strategies to reduce the incidence of financial abuse of people with dementia and to resolve cases satisfactorily emerged from the research. These include reporting of financial abuse of people with dementia, and registration and monitoring of EPOAs. These measures are not universally supported and the surrounding debates are examined in the paper.

Our research findings have implications for many stakeholders including lawyers, police, banks and community services. Many agencies have a role to play in reducing the incidence and impact of financial abuse of people with dementia. Based on the findings of our research, we made several recommendations for changes that could address the issue of financial abuse of people with dementia.

**Aim 3: Educate service providers and people with dementia and carers about how to safeguard themselves and prevent financial abuse.**

This phase of the project is still being implemented. We are using every available opportunity to disseminate the research findings and recommendations through presentations and articles. The release of the NSW Interagency Policy on Preventing and Responding to Elder Abuse will assist with prevention and reporting of financial abuse by outlining obligations of individuals and organisations. Our research should help service providers identify warning signs in order to comply with this policy.

The education session for AlzNSW staff will be held in late 2014.

We are currently developing the Help Sheet for people with dementia and carers.

This phase of the project will now also be supported through the Financial Abuse Interagency established following the launch of the discussion paper. It is an ongoing process that involves the cooperation and collaboration of many organisations and individuals. Aim 1 and 2 will continue to be an ongoing focus for this interagency group.

Our overarching aim is “to reduce the incidence of financial abuse of people with dementia” as a long-term goal. The research highlighted that there is no one solution that will eliminate financial abuse, and it will require the collaborative efforts of many stakeholders. We view this project as a first step towards this.
Conclusion and recommendations

What is your conclusion?
Our view is that the project was successful in achieving its stated aims, but that the issues highlighted will take considerable effort by many stakeholders for a long period of time before financial abuse is reduced.

What are your recommendations for improvements both for the intended audience of your project, and for the strategy you used to achieve your aim? What would you do differently next time?
Our strong preference would have been to include more interviews with people with dementia or their carers to describe their experiences of financial abuse. However, given the sensitivity of the issue this was very hard and we did not totally foresee this. Anonymous surveys may have elicited more stories for the research.

We identified the need for further research, particularly with perpetrators to understand why they commit financial abuse. Knowing this would contribute to a greater understanding of how to prevent it. This is an approach fraught with ethical issues.