

NSW AGEING AND DISABILITY COMMISSION

**SUBMISSION TO THE NSW LEGISLATIVE COUNCIL
INQUIRY INTO THE PREVALENCE, CAUSES AND
IMPACTS OF LONELINESS IN NEW SOUTH WALES**

NOVEMBER 2024

1. Background and focus of our submission

The NSW Ageing and Disability Commission (ADC) was established on 1 July 2019 with the objectives of protecting older people and adults with disability from abuse, neglect and exploitation, and protecting and promoting their rights.

A key role of the ADC is to respond to reports about older people (65 years and over or, if Aboriginal and/or Torres Strait Islander, 50 years and over) and adults with disability (18 years and over) in NSW who are subject to, or at risk of, abuse, neglect and exploitation in their family, home and community, including by providing advice, making referrals, conducting investigations, and taking safeguarding actions.

The ADC also has a general oversight and coordination role in relation to the Official Community Visitor (OCV) scheme. OCVs are independent Ministerial appointees who visit people living in residential care in NSW, including adults living in disability supported accommodation and assisted boarding houses, and children and young people living in residential out-of-home care.

This submission has been informed by our handling of reports about older people and adults with disability, and by the observations and experience of OCVs who visit people living in residential care. Guided by this experience, the focus of our submission is on highlighting the link between loneliness, social isolation, and abuse, neglect and exploitation of older people and adults with disability and identifying areas for attention to reduce prevalence and impact.

2. Loneliness and social isolation of older people and adults with disability

The ADC welcomes the inquiry into the prevalence, causes and impacts of loneliness in NSW and the acknowledgement of loneliness and social isolation as major public health issues. Problematic levels of loneliness are not equally distributed across the population, and adults with disability and older people are among those at higher risk of loneliness and social isolation.

Research has highlighted that disability-related inequalities in loneliness have persisted for two decades in Australia without improvement, with findings showing that people with disability are 1.5 to 1.9 times more likely to experience loneliness than people without disability. These inequalities are even more significant for individuals living with intellectual or learning disabilities, psychological disability, and brain injury or strokeⁱ.

Loneliness and social isolation often feature in reports handled by the ADC about adults with disability and older people alleged to be subject to, or at risk of, abuse, neglect and exploitation in their family, home and community.

Brief data context

Between 1 July 2019 and 30 June 2024, the ADC received 18,896 statutory reports about abuse, neglect and exploitation of older people and adults with disability in NSW. Of these reportsⁱⁱ:

- Three-quarters have been about older people, including older people with disability; a quarter has concerned adults with disability (who were not older people).
- Most have involved more than one form of alleged abuse, including psychological abuse, financial abuse, neglect, physical abuse and/or sexual abuse.
- The main subjects of allegation have been relatives (such as adult children, parents, siblings, and grandchildren) and current or former intimate partners of the older person

or adult with disability.

More detailed data, including quarterly, annual, and five-year data reports, are available on our website.ⁱⁱⁱ

In reports handled by the ADC, we have repeatedly identified social isolation and loneliness of adults with disability, older people and family carers, and seen the significant impact on these populations. Among other things, we frequently note individuals who have not had contact with anyone outside of their home for a long time, including people in dire circumstances.

Our work has highlighted loneliness and social isolation as:

- a) Contributing factors to abuse, neglect and exploitation.
- b) An often-intentional consequence of abuse, neglect and exploitation, including domestic and family violence (DFV).
- c) Issues that are inadequately considered and addressed across service systems, including aged care, disability, and health services.

3. Loneliness and social isolation are contributing factors to abuse, neglect and exploitation

Reports handled by the ADC highlight social isolation and loneliness as key risk factors for abuse, neglect and exploitation of older people and adults with disability.

4.1 Targeting by external parties for exploitative purposes

Among other things, we have repeatedly identified adults with disability and older people experiencing loneliness and social isolation who have been specifically targeted by, or susceptible to, exploitative parties, including:

- being subject to online relationship scams and exploitation
- being targeted and financially exploited by external parties, including individuals they meet in the community, and people they trust, such as current or former paid workers and 'friends' (see case examples 1 and 2).

A lack of quality social connections can result in the placement of trust in individuals who would not typically be relied on as supporters. This increases the risk of, and their susceptibility to, abuse, including (but not limited to) financial exploitation.

In matters handled by the ADC, the targeting for exploitative purposes of older people and adults with disability who have minimal or no meaningful social connections has occurred across locations, socioeconomic circumstances, and accommodation settings. It has included:

- older people in residential aged care without family or other visitors who have formed a 'friendship' with an aged care worker(s), and been financially exploited to provide the individual with money and assets, and to make them their enduring power of attorney and/or beneficiary in their will
- adults with disability and older people who live alone, become 'friends' with someone they have met in the community (such as at a club, pub, church, or shopping centre), agree to provide the individual with accommodation in exchange for company and/or support, and are subject to abuse, including financial exploitation, coercive control and neglect
- older people in retirement villages without social connections who become 'friends' with another resident of the village who provides them with some day-to-day assistance (such as with shopping, paperwork, transport to health appointments) but

also exploits them for financial gain.

The common elements in these matters have been that the adult with disability or older person has had no or few social connections, has been experiencing loneliness, and has been receptive to what they are intended to see as a genuine and mutually beneficial relationship. In many cases, the adult with disability or older person becomes so convinced that the party is their friend and the relationship is genuine that it can be very difficult to persuade them otherwise, notwithstanding evidence of the abuse.

Case example 1¹

Alexander has a disability affecting his mobility and cognition following a childhood accident. After his brother died, Alexander was left living alone in his home, with no family support, and experiencing depression and chronic loneliness. He met Daniel who needed a place to stay, and Alexander allowed him – and later, Daniel’s girlfriend Kate – to move into his property.

Over the next 12 to 18 months, Daniel and Kate filled Alexander’s home with their belongings. Alexander became isolated to his room, and Daniel began using Alexander’s disability support pension to support his own lifestyle. Daniel provided little to no support to Alexander and, as a result, Alexander’s health and wellbeing declined. Over time, his mobility worsened to the point where he would hardly leave his bed and was unable to walk without assistance.

A concerned neighbour reported the situation to the ADC. When ADC staff conducted a home visit, they found Alexander in a critical state, isolated to his room while Daniel and Kate had taken over his home. In initial discussions with the ADC, Alexander supported Daniel, viewing him as a friend and carer.

The ADC arranged for Alexander to be admitted to hospital for urgent care. While in hospital, he reconnected with an old family friend in addition to receiving assistance from hospital staff and the ADC. Over time, Alexander realised that he had been manipulated and agreed to access legal help to evict Daniel and Kate. He is now receiving support through the NDIS and has increased engagement with others.

Case example 2

The ADC received a report about potential financial exploitation of Margaret, an older woman with dementia and declining decision-making capability who lived in a retirement village. The report alleged that thousands of dollars had been withdrawn from Margaret’s bank accounts and a neighbour in the retirement village had sought to gain access to her accounts after getting her to appoint them as her Enduring Power of Attorney (EPOA) instead of her family member.

Margaret considered the neighbour to be a good friend, and she relied on them for company and some day-to-day support, including some grocery shopping, appointments, social activities and housework.

After preliminary inquiries, the ADC commenced an investigation. We found that almost \$300,000 of Margaret’s funds had been used to pay for items that benefitted the neighbour, either directly or indirectly. This included the cost of the neighbour’s retirement village unit, legal services, and motor vehicle.

¹ All case studies in this submission have been de-identified to protect the identity of the adults.

We found that Margaret could not recall any information about her financial circumstances and her neighbour had been aware of Margaret's declining memory and decision-making ability for a long time. Shortly before the report to the ADC, Margaret had signed Enduring Guardian and EPOA instruments naming the neighbour as her guardian and attorney. Our investigation identified that, at the time of these appointments, Margaret did not have sufficient capability to understand what was happening.

4.2 Abuse, neglect and exploitation by relatives and partners

As noted earlier, most reports to the ADC involve alleged abuse by the relatives of the adults with disability and older people, or by their current or former intimate partners. In a range of these reports, social isolation and loneliness of the adult has made it easier for the abuse to occur and to continue undetected. Among other things, this is because there are no external eyes on the adult to identify potential concerns about their presentation and circumstances, ascertain the adult's views and wishes, or ensure connection to necessary supports and services.

A key feature of many of these reports has been the dependence of the adult on the relative or partner for day-to-day support. The social isolation and loneliness mean that the adult is heavily reliant on the person to meet their increasing support needs, typically unable to independently change the situation, and reluctant to do anything that would put that support at risk (even when that support is grossly inadequate or provided in the context of abuse). In these complex circumstances, the adult's reluctance to take action against the subject of allegation can be for several reasons, including the potential for family breakdown or conflict, fear of losing a source of companionship and support (see case example 3), and the related fear that they may have to go into residential care.

Case example 3

The ADC investigated a report of alleged financial abuse of an older woman, Mary, by her son. Mary lives in a residential aged care facility and has limited access to the community. She told the ADC that her son uses her bank card to make purchases for her. Mary said that her son would not steal from her but consented to the investigation for her own peace of mind.

The ADC alerted Mary's bank that we were investigating alleged financial abuse and that Mary's bank card was not in her possession. The ADC asked the bank to consider putting safeguards on Mary's account, who identified over \$100,000 in suspicious transactions. The ADC referred the potential fraud to NSW Police.

When the ADC showed Mary her bank statements, she was shocked to see the amount of funds that were missing. Mary told the ADC she felt stuck because she had no-one else to help her get the things she needed in the aged care facility and she did not want her son to stop visiting her.

4.3 Social isolation, loneliness and neglect

The ADC has observed that the absence of strong support networks and meaningful connections increases the likelihood of older people, adults with disability and carers 'falling through the gaps' in accessing essential services, with a resulting high risk of neglect. Since the start of the ADC in 2019, 21% of the reports about older people and 26% of the reports about adults with disability have involved allegations of neglect^{iv}.

The most common neglect allegations have related to fundamental failures to meet the adult's support needs (including day-to-day care), and their health and medical needs. The impact on the older people and adults with disability at the centre of many of the reports has been substantial – ranging from hunger, poor hygiene, and lack of contact with the community, through to malnutrition, untreated serious medical conditions, and significant harm.

The ADC has increasingly received reports involving more substantial neglect – including individuals who have been in very poor health and dire circumstances at the time of admission to hospital, and who have died shortly afterwards.

We are currently undertaking a research project on neglect of older people and adults with disability in their family, home and community (including self-neglect)^v. A key component of the project involves analysis of data from approximately 1,460 reports to the ADC about neglect of older people and adults with disability over a two-year period to better understand the factors involved and identify strategies for prevention and early intervention. Social isolation is one of the factors that is being examined as part of this research. UNSW has been engaged to produce the research report, which is due to be completed in June 2025.

4.4 Social isolation and loneliness make it harder to detect and report abuse

Social isolation and loneliness magnify the barriers faced by adults with disability and older people in disclosing abuse and obtaining assistance. This includes situations in which they:

- have no contact with external parties and/or access to a telephone to seek assistance
- lack confidence and knowledge to obtain help
- heavily rely on the subject(s) of allegation for support.

4.5 Risks associated with artificial communities

For some older people and adults with disability, licensed clubs have been seen as a reliable way to reduce loneliness, feel welcomed into a 'community', and spend time around others in a warm, dry and consistent space. At times, these environments have provided an alternative social option for those who do not wish to participate in group events; transportation to and from the venue; and accessible facilities.

However, they can also provide ready access to gambling, increase financial risks, unhelpfully frame gambling as attractive and a social benefit, and can make it easy for parties to identify adults with disability and older people who do not have social networks and may be able to be exploited for financial gain.

4. Loneliness and social isolation are often-intentional consequences of abuse, neglect and exploitation

Abuse, neglect and exploitation is a direct cause of loneliness and social isolation for older people and adults with disability. In matters handled by the ADC, this has included situations where (among other things) the older person or adult with disability:

- is subject to coercive control, including the perpetrator preventing or restricting access to the community, preventing access to necessary aids and equipment, and controlling what they do, who they see, and who they talk to (see case example 4)
- has been forcibly isolated and locked away for prolonged periods of time by the perpetrator of abuse, having no interaction with friends, family, or society (see case example 5)
- is financially exploited, including adult children threatening to cut off the older

person's contact with them or their grandchildren unless the older person provides money or assets, or makes changes to their will.

It is important to recognise that social isolation and loneliness is not just a consequence of abuse, neglect and exploitation – it can often be an intentional part of the abuse. Isolating the older person or adult with disability is a deliberate strategy to exert control, destroy the adult's confidence and autonomy, increase dependence, and perpetrate other abuse.

These issues are magnified further when considering that many older people and adults with disability in these circumstances may have pre-existing reliance on the perpetrator due to their support needs.

Case example 4

The ADC investigated a report about a woman with disability, Sue, who was alleged to be subject to domestic violence by her husband, who was also her carer. Sue relied on a wheelchair for mobility and required physical assistance with all daily tasks.

The ADC's investigation identified that, among other forms of coercive control, Sue had no access to banking or her finances. Her husband had control over all financial and other aspects of her life, including refusing her access to funds for basic items such as creams to help her skin integrity.

Sue only had an old nightdress for clothing and was afraid to request funds from her husband for clothes; she said it would make him angry. As a result, she felt too embarrassed to go into the community and was extremely isolated.

Case example 5

The ADC received a report about a man with intellectual disability, Philip, who was alleged to have been kept in a shed by a family member for many years. The report stated that Philip had limited access to food, warmth and no access to his own funds and was subject to threats of violence. The ADC liaised with police and the Aged Care Assessment Team to arrange transportation for Philip to hospital, where he was found to be dehydrated and malnourished. The ADC visited him while in hospital and with his consent made a referral for disability advocacy.

Philip described being kept in the shed for a period of 16 years, with the backyard boarded up. He had access to a tap in the yard and a bucket for personal hygiene and had no access to his funds. He had no identity documents and reported he had not been allowed to leave the property. We commenced an investigation and obtained records from Centrelink and Medicare to establish where Philip's pension was going, whether a carer payment was being paid, and his access to health care services. We provided supporting documentation to assist him to obtain his birth certificate. We referred the allegations of neglect back to police and made an NCAT application for guardianship and financial management to enable Philip to set up support services and his finances.

A guardian and financial manager were appointed for a period of three months to enable consideration of Philip's decision-making capability as he recovered from the alleged neglect and re-entered the community after an extended period of isolation. An application for the NDIS was made by hospital staff, and Philip subsequently received NDIS supports and was able to access supported accommodation.

5. Social isolation and loneliness of people living in residential care

Living with others in a residential care setting does not, in and of itself, prevent loneliness or social isolation. In addition to examples provided in this submission regarding older people living in residential aged care, Official Community Visitors (OCVs) visiting people living in disability supported accommodation, assisted boarding houses and residential out-of-home care premises in NSW have frequently raised concerns about the social isolation and loneliness of residents.

In particular, OCVs have raised concerns that:

- Adults with disability in NDIS-funded supported accommodation have minimal opportunity to meaningfully engage and participate in the community. OCVs have repeatedly noted individuals for which 'community access' is limited to drives with their co-residents to venues such as parks where they have limited or no contact with others; and trips to fast food 'drive-thru'.
- There is an inadequate focus in NDIS services on supporting participants to gain social and community connections of their own, guided by their interests and preferences. By way of example, an OCV advised the ADC of a visit in which they had identified that staff had refused to take a resident to a football game they requested, because the staff member was not interested.
- Similarly, insufficient attention and value is placed on assisting residents to build their capabilities and skills in connecting with others. An OCV provided an example of a person with disability who was receiving regular speech therapy that was focused solely on daily tasks such as meal planning and self-care. The OCV ascertained the person's wishes and advocated for the speech therapy to incorporate topics relating to building friendships and engaging in conversations. The OCV noted that what appeared as a seemingly minor change significantly helped the person to form positive social connections and to engage with others.
- People with disability in supported accommodation often attend day programs and activities with the same people they live with (particularly in regional areas), limiting opportunities to develop social skills and build broader social connections. OCVs advised that it is often incorrectly assumed that participants have meaningful friendships with their co-residents, and questions are rarely asked about whether individuals have the levels of social connection and friendship they desire.
- The quality and quantity of communication between staff and residents in accommodation services is a contributing factor to loneliness among adults with disability in residential care. OCVs noted that the focus in services is often on staff completing the required chores within their shift, and an inadequate focus is placed on meaningful engagement.
- Young people are often placed in geographically isolated accommodation services. In addition to exacerbating their levels of isolation and hindering the opportunity to build social connections, OCVs noted that this situation often results in young people engaging in risky behaviours, such as hitchhiking with strangers and forming unsafe relationships online.

6. Additional causes of loneliness and social isolation

Older people and adults with disability are more likely to experience discrimination, marginalisation, and social exclusion due to a dominant mainstream culture that condones ageist and ableist views, beliefs, and values. This environment discourages social participation and further exacerbates the social isolation and loneliness of older people and adults with disability.

Additional, and often intersecting, drivers of loneliness and social isolation among older people and adults with disability observed in reports handled by the ADC include:

- familial breakdown and conflict
- isolation by choice
- geographical location and limited transportation options
- life events, change in circumstances and/or health
- limited availability of services and supports
- lack of employment opportunities and/or support to return to employment
- socioeconomic disadvantage.

7. Impact of loneliness and social isolation

As highlighted throughout this submission, the impact of loneliness and social isolation on older people and adults with disability can be devastating, including:

- preventable death
- contributing to, or worsening, existing physical and mental health issues
- loss of self-esteem, confidence, and further social withdrawal
- reduced motivation for self-care, medical attention, and other health-promoting habits.

Additionally, the ADC has noted that social isolation is a factor in a significant number of reports about self-neglect, squalor, and hoarding. Living alone without social connections or meaningful activities can adversely affect individuals' motivation to leave their home and take care of themselves and their living environments. The issue of self-neglect is complicated further when considering the additional support that older people and adults with disability may require to complete such tasks.

8. Prevention and mitigation of loneliness and social isolation of older people and adults with disability

Important safeguarding strategies used by the ADC in response to many reports about abuse, neglect and exploitation of older people and adults with disability tend to involve improving the supports for the adult and increasing their connections to external parties and the community – guided by their views and wishes. While varying according to the individual circumstances of the report and the adult, relevant actions by the ADC can include working with the adult and others to:

- assist the adult (and carer/family where appropriate) to access necessary supports – such as aged care, disability, carer, health and mental health services
- reconnect the adult with key supporters, including estranged family members and friends
- enable access to communication options
- enable access to the community and social activities.

In our experience, there is a need for increased attention to be paid to social isolation and chronic loneliness of adults with disability and older people, and to initiatives and approaches that aim to prevent and address these concerns.

Strategies

The Ageing Well in NSW Seniors Strategy and Action Plan include initiatives that are relevant to preventing or reducing loneliness and social isolation of older people, including through developing and increasing participation in inclusive communities. The Reducing Social Isolation for Seniors grants program is part of the current action plan, among a range of other

initiatives across arts, technology, events, and employment^{vi}.

Australia's Disability Strategy also includes areas that are relevant to loneliness and social isolation of people with disability, including strategies focused on employment, inclusive homes and communities, and community attitudes. We note that an action plan has yet to be developed in relation to 'Inclusive homes and communities'^{vii}.

The NSW Disability Inclusion Plan also includes a focus on creating liveable communities and positive community attitudes^{viii}.

While these overarching strategies directly or indirectly relate to loneliness and social isolation of older people and people with disability, there appears to be significant scope to strengthen approaches and coordination in relation to these issues in NSW – specifically for these cohorts, for carers, and more broadly. In this regard, we support the recommendation of the Mental Health Coordinating Council for the development of a 'Tackling Loneliness' Strategy for NSW. In our view, this would need to be informed by evaluation of the evidence relating to the effectiveness of strategies for preventing and addressing social isolation and loneliness of older people and adults with disability, such as (among other things) those identified in existing Commonwealth and NSW plans/strategies; intergenerational approaches such as 'Old People's Home for 4 Year Olds'; and outreach services, such as the aged care visiting program.

Service providers and direct care workers

Paid workers are the main reporters to the Ageing and Disability Abuse Helpline about older people and adults with disability^{ix}. Service providers and staff are in a valuable position and powerfully placed to identify and respond to the signs and impacts of loneliness and social isolation of adults with disability, older people, and family carers.

In the experience of the ADC, there are opportunities to strengthen the safeguards afforded by service providers and staff (including, but not limited to, aged care and disability services) in relation to social isolation and loneliness of older people, adults with disability, and family carers, including actions to ensure that:

- paid workers are supported and equipped with the skills and resources needed to identify and respond to loneliness and social isolation, including in relation to people living in residential care
- service providers are more clearly and consistently conduits for older people, adults with disability, and family carers to link to meaningful connections, as opposed to being their only source of external contact
- the existence or risk of social isolation and loneliness is considered and assessed as part of the processes for determining the supports required by the older person or adult with disability (including aged care assessment, NDIS planning, and health assessment processes)
- services have sufficient flexibility to attend the home or preferred location of the older person or adult with disability and do not solely rely on the adult being able to freely access them
- 'social support' for older people is not limited to transport for shopping or daily telephone check-in calls, but enables access to broader opportunities for meaningful social engagement
- proactive steps are taken to enable access to adequate and appropriate communication support
- there is improved guidance for, and quality monitoring of, relevant NDIS providers in relation to participant engagement and involvement in meaningful activities, social

connections, and community inclusion.

Volunteering

Volunteering provides significant benefits to the volunteer and community, including the opportunity to be involved in meaningful activities of interest, to feel useful and valued, and to gain greater social contact and engagement. In our view, there would be merit in exploring opportunities to increase awareness of, and access to, volunteering opportunities for adults with disability and older people in NSW.

A recent report on the involvement of older people in volunteering in NSW has highlighted the benefits to older people and the community and identified that 54.5% of people aged 65 and over in NSW contributed as volunteers in 2023^x. However, while there is a NSW Volunteering Strategy 2020 – 2030, it is not evident whether, and to what extent, people with disability are included. There would be significant value in developing and promoting specific strategies to better support the appropriate involvement of people with disability in volunteering.

In addition, noting that most of the older people volunteering heard about it via word of mouth, there would be benefit in exploring other options to increase awareness – for example, proactively providing information to Seniors Card holders.

ⁱ Bishop, G.M., Llewellyn, G., Kavanagh, A.M. *et al.* Disability-related inequalities in the prevalence of loneliness across the lifespan: trends from Australia, 2003 to 2020. *BMC Public Health* 24, 621 (2024).

<https://doi.org/10.1186/s12889-024-17936-w>

ⁱⁱ https://ageingdisabilitycommission.nsw.gov.au/documents/reports-and-submissions/ADC_Five_Year_Summary_Report_Card_2019_-_2024.pdf

ⁱⁱⁱ See <https://ageingdisabilitycommission.nsw.gov.au/tools-and-resources/dashboard-data.html>

^{iv} https://ageingdisabilitycommission.nsw.gov.au/documents/reports-and-submissions/ADC_Five_Year_Summary_Report_Card_2019_-_2024.pdf

^v The research project is being funded by the Department of Communities and Justice.

^{vi} NSW Government, *Ageing Well in NSW: Seniors Strategy 2021 – 2031*, and *Ageing Well in NSW: Action Plan 2023 – 2024*, <https://dcj.nsw.gov.au/community-inclusion/seniors/ageing-well-in-nsw-seniors-strategy-2021-2031/publications.html#Ageing0>

^{vii} Commonwealth of Australia (Department of Social Services) 2021, *Australia's Disability Strategy 2021 – 2031*, <https://www.disabilitygateway.gov.au/document/3106>

^{viii} NSW Government, *NSW Disability Inclusion Plan 2021 – 2025*, <https://dcj.nsw.gov.au/documents/community-inclusion/disability-inclusion/nsw-disability-inclusion-plan/nsw-disability-inclusion-plan.pdf>

^{ix} https://ageingdisabilitycommission.nsw.gov.au/documents/reports-and-submissions/ADC_Five_Year_Summary_Report_Card_2019_-_2024.pdf

^x The Centre for Volunteering (2024), *NSW State of Volunteering: Older Persons and Volunteering*